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ABSTRACT

This document contains transcripts of witness testimony and prepared statements from the Congressional hearing called to review the need for a national health care policy for long-term care. Opening statements are presented from committee chairman Claude Pepper and from Representatives Sala Burton and Barbara Boxer. Testmonies are presented from representatives of the state of California including the lieutenant governor, the chairwoman, Assembly Committee on Aging and Long-Term Care, and the chairman, Senate Subcommittee on Aging; and from representatives of San Francisco city and county agencies. Additional testimony is provided from three panels of witnesses: panel one includes Alzheimer's patients and caregivers, pediatric home-care recipients and caregivers, and representatives of home health service agencies and support groups; panel two includes representatives from the University of California Department of Family and Community Medicine and Aging Health Policy Center, the president of On Lok Senior Health Services, and the editor of a journal related to long-term and home health care; panel three includes a supervisor and a former supervisor of in-home health service agencies. The focus of the hearing is the federal role in structuring a comprehensive continuum of care to address preventative, acute, and chronic health care needs. The appendix contains additional material submitted for the record. (MCF)

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LONG-TERM CARE: NEED FOR A NATIONAL POLICY

ED261290

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE

OF THE

SELECT COMMITTEE ON AGING HOUSE OF REPRESENTATIVES

NINETY-EIGHTH CONGRESS

FIRST SESSION

DECEMBER 15, 1983, SAN FRANCISCO, CALIF.

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LONG-TERM CARE: NEED FOR A NATIONAL POLICY

THURSDAY, DECEMBER 15, 1983

HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON AGING,
SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE,
San Francisco, Calif.

The subcommittee met, pursuant to call, at 9 a.m., in the Ceremonial Courtroom, Federal Building, 450 Golden Gate Avenue, San Francisco, Calif., Hon. Claude Pepper (chairman of the subcommittee) presiding.

Members present: Representatives Pepper of Florida, Burton of California, and Boxer of California.

Staff present: Bill Halamandaris, staff director; Kathy Gardner Cravedi, assistant staff director; and Melanie Modlin, executive assistant.

OPENING STATEMENT OF CHAIRMAN CLAUDE PEPPER

Mr. PEPPER. Ladies and gentlemen, I am Claude Pepper, a Member of the House of Representatives from Miami, Fla. Florida is a State down to the southeast from here and I'm very proud to have the honor and privilege of being here with all of you this morning.

I am always delighted to have an opportunity to come to this great State of California and I think that everyone recognizes that the beautiful city of San Francisco is one of the unique and attractive cities of the world. So, it is always a special pleasure for me to be able to come here.

I understand that the notice went out that the hearing was to begin at 10:00, so there will be many more people, I am sure, coming in this morning. We are delighted to have all of you here and grateful to you for manifesting the interest that you show, by your presence, in the health and long-term care of the elderly people of this country.

Our Subcommittee on Health and Long-Term Care of the House Select Committee on Aging is conducting this hearing.

I am very proud to have with me here today several fine legislators from the State of California, and after I make a brief statement, I'll call upon them to make such statement as they will.

One of your distinguished Members of the House of Representatives who has taken up the mantel of her late, great husband and is discharging her duties as he did his with great distinction, and

who is highly esteemed and revered by the Members of the House of Representatives, Mrs. Sala Burton.

Mrs. BURTON. Thank you. Thank you.

Mr. PEPPER. I'm also very pleased to have here with us this morning to honor us by her presence another of your very distinguished Members of the House of Representatives, highly esteemed and revered by Members of the House an able representative of a district here in this area, Mrs. Barbara Boxer.

Mrs. BOXER. Thank you so much.

Mr. PEPPER. Here on my left, we are honored to have with us this morning the very gracious and distinguished lady who is chairman of the California Assembly Health and Long-Term Care Committee, the health committee on the elderly. She is primarily concerned with the elderly and she is honoring us with her presence this morning, Jean Moorhead. There's a lovely lady.

She is a member of the assembly of your legislature and has been innovative in this great field of the elderly.

You have many elderly citizens in your State, as we do in Florida, and Mrs. Moorhead has been one of those who has been primarily concerned in the assembly of your legislature about the well-being of older people in this country. So, we are particularly pleased to have you here.

Ms. MOORHEAD. Thank you.

Mr. PEPPER. And we also have another great champion of the elderly, a man who has done much for the cause of the elderly in your great State. He, too, is chairman on aging in the Senate of your legislature. We are honored and proud to have with us this morning Senator Mello, chairman of the Committee on the Elderly in the Senate of your very great State of California. So, we are particularly pleased to have him here.

Also, another lady who is very interested and very active in the cause of the elderly, Ms. Joyce Ream. Ms. Ream, we are very pleased to have you here this morning.

Ms. REAM. Thank you.

Mr. PEPPER. Thank you for being kind enough to join us this morning. For the most part Federal and private insurance companies are designed to finance health care treatments only when illness is associated with periods of hospitalization.

Our health care system virtually rules out financial assistance for care that may prevent or postpone costly and premature institutionalization such as immunization, pediatric and adult home care and other supportive services.

Furthermore, when institutionalization is needed, Federal and private insurance does not exist to any appreciable extent for custodial nursing home care. Only $200,000,000 was covered by insurance in 1981 for nursing home care, for example. This is less than 1 percent of the Federal-State programs for the poor, medicaid paid the lion's share, about 50 percent.

Almost all the rest is paid out of the pockets of the families of those afflicted by long-term illness.

I regret to say that when in 1965 medicare was established, the elderly were spending about 20 percent of their own income for medical care. Then came the institution of medicare and that share of spending by the individual, out of his or her own funds, dimin-

ished or was reduced. Now, due to the increasing cost of hospital and medical care and the expense of the providers, senior citizens are again spending about 20 percent of their personal income on their medical care in spite of the assistance they get, essential and valuable as it is, from medicare. Nowhere in our society are families left so unassisted as they are in meeting the financial and emotional burden of caring for an Alzheimer's patient or a chronically ill pediatric patient.

Medicare does not cover that terrible disease, Alzheimer's, although it is now the fourth leading killer in our country.

We had a hearing not long ago where a lady and her sister from New York appeared as witnesses. Their mother was stricken by Alzheimer's disease. They had been keeping her in an institution for some time. One of these daughters testified that within 4 months every penny of the assets of that family would have been exhausted in trying to provide care for the mother who was the victim of Alzheimer's disease.

I'll say more about this subject later, but a little bit ago, a lady visited me in my office in Washington and she said, "I have had to go back from my retirement to employment in order to take care of my husband who is the victim of Alzheimer's disease in order to keep him in an institution. It takes every penny that I can make."

"But," she said, "Mr. Pepper, recently I had a letter from a friend of mine in England who said her husband had Alzheimer's disease. He was in an institution, but it didn't cost her a penny."

She said, "Why is that?"

I said, "Well, in England they have a national health insurance program and we don't have one and that's one of the problems that we're struggling with now."

I have been talking to the Governor about this. He has honored us with his presence here this morning, the Lieutenant Governor of your great State who has long been concerned about this subject. We were talking about how we can develop a national medical system in this country under which every man, woman, and child in this great Nation can get, within his or her means, the medical care that he or she should have to live longer, to live healthier, and to live happy lives.

Although we live in a rich Nation, there are terrible gaps in our health and social programs which underscore this sad truth: There is no meaningful long-term care policy today in the United States.

You may recall the case of Katie Beckett, a 3-year-old child, as an example of government regulations gone awry. Medicaid paid for Katie's care while she was in a costly hospital, but prohibited payment for the less costly and more humane care she could get at home.

Although Katie was eventually granted a presidential waiver for care at home, she was the lucky one. There are hundreds of thousands of Katies who remain the victims of a health care delivery system not geared to providing services in the least restrictive environment, the home.

So, one of the things that we are concerned about this day, particularly, is more preventive care for people, maybe saving them from having to go into a hospital or a nursing home, and more home care.

You may also recall the words of an Arizona man, the husband of an Alzheimer's victim, who told our subcommittee this year, "I find it strange that if my wife had a disease from which she could recover, or was ill with something like cancer where she could be placed in a hospice, she could be helped financially, but we are told with Alzheimer's disease there is no financial assistance available."

You can imagine the shock of our subcommittee when the daughter of an Alzheimer's patient testified, "My doctors told me that the only way to get assured financial assistance for my mother would be to break her arm and have her put in the hospital and when her arm healed, break it again and keep breaking it if you want to assure financial assistance."

Of course, her doctor was not serious about going to such lengths, but the point was unfortunately well made, because the essential elements of treating Alzheimer's patients can be provided in the home and do not require hospitalization.

Financial assistance is minimal at best.

Today we will hear directly from Alzheimer's patients and their care givers and pediatric home care patients as well as from their care givers.

They will relate to us their personal experiences and their frustrations in attempting to secure the health care they so desperately need.

With the pending insolvency of the medicare program, the United States is now at a crossroads. In about 4 years the medicare program, unless we revise it, strengthen it, and make it sound and secure, as we did social security, will not be able to pay its bills.

So that's the challenging job ahead of us which we've got to do.

The purpose of our hearing will be to explore what the Federal role might be in structuring a comprehensive continuum of care, a long-term care policy capable of addressing the preventative, acute and chronic health care needs of our Nation's citizens.

Today's hearing will point out how we need a health care system which provides more service, more efficiency and for less money.

California has been the leader in attempting to do just that. We look forward to hearing the testimony of those who have helped charter the development of long-term care alternatives in California.

Now, may I invite you to have something to say. Mrs. Sala Burton will make such comments as she would like.

[The prepared statement of Chairman Pepper follows:]

PREPARED STATEMENT OF CHAIRMAN CLAUDE PEPPER

Ladies and gentlemen. Members of the subcommittee, and distinguished guests. It is a pleasure to join Hon. Barbara Boxer and Sala Burton—both of whom represent the State of California in Congress—in convening this Subcommittee hearing on "Long-Term Care: The Need for a National Policy." Joining our congressional delegation on the dais today are some distinguished Representatives from the State of California, including Hon. Willie Brown, Jr., Speaker of the House; the Honorable Jean Moorhead, Chairperson of the California Assembly on Aging and Long-term Care; the Honorable Henry J. Mello, chairman of the Senate Subcommittee on Aging; and the Honorable Joyce Ream, director of the San Francisco City and County Commission on Aging.

The subject of our hearing is extremely important. Long-term care for *all* Americans stands today as the most troubled, and troublesome, component of our entire health care system.

For the most part, Federal and private insurance programs are designed to finance health care treatment only when illness is associated with periods of hospitalization. Our health care systems virtually rule out financial assistance for care that may prevent or postpone costly and premature institutionalization, such as immunizations, pediatric and adult home care and other supportive services. Furthermore, when institutionalization is needed, Federal and private insurance does not exist to any appreciable extent for custodial nursing home care. Although the nation spent about $25 billion in 1981 for nursing home care, only $200 million was covered by insurance—under 1 percent! The Federal-State program for the poor, medicaid, paid the lion's share, about 50 percent. Almost all the rest is paid out of the pocket by the families of those afflicted by long-term illness.

Nowhere in our society are families left so unassisted as they are when meeting the financial and emotional burden of caring for an Alzheimer's patient or a chronically ill pediatric patient. They reflect the largest gaps in our health and social programs and underscore the sad truth that there is no meaningful long-term care policy in the United States today.

You may recall the case of Katie Beckett, a three-year-old child, as an example of government regulations gone awry. Medicaid would pay for Katie's care while she was in a costly hospital, but prohibited payment for the less costly and more human care she could get at home. Although Katie was eventually granted a Presidential waiver for care at home—she was the lucky one—there are hundreds of thousands of Katies who remain victims of a health care delivery system not geared to providing services in the "least restrictive environment"—the home.

You may also recall the words of an Arizona man—the husband of an Alzheimer's victim—who told our subcommittee earlier this year, "I find it strange that if my wife had a disease from which she could recover, or was ill with something like cancer where she could be placed in a hospice, she could be helped financially. But, we are told with Alzheimer's disease there is no financial assistance available."

You can imagine the shock of our subcommittee when the daughter of an Alzheimer's patient testified, "my doctor told me that the only way to get assured financial assistance for my mother would be to break her arm, and have her put into a hospital. When her arm heals, break it again, and keep breaking it if you want to assure financial assistance." Of course, her doctor was not serious about going to such lengths, but the point was, unfortunately, well made: Because the essential elements of treating Alzheimer's patients can be provided in the home—and do not require hospitalization—financial assistance is minimal at best.

Today, we will hear directly from Alzheimer's patients and their caregivers, and pediatric home care patients, as well as from their caregivers. They will relate to us their personal experiences and frustrations in attempting to secure the health care they so desperately need.

With the pending insolvency of the medicare program, the United States is now at a crossroads. We are forced to consider the future of its health care delivery system. The purpose of our hearing will be to explore what the Federal role might be in structuring a comprehensive continuum of care—a long-term care policy—capable of addressing the preventative, acute and chronic health care needs of our Nation's citizens.

Today's hearing will point out how we need a health care system which provides more service, more efficiently, and for less money. California has been a leader in attempting to do just that. We look forward to hearing the testimony of those who have helped charter the development of long-term care alternatives in California.

Our first witness today will be Lieutenant Governor Leo McCarthy. His efforts in health care are well known and well regarded. We look forward to your valuable testimony. Thank you.

STATEMENT OF REPRESENTATIVE SALA BURTON

Mrs. BURTON. Thank you, Mr. Chairman.

I would like to congratulate you, Mr. Chairman, for holding these hearings. I know what a champion you are of health in this country.

You have touched upon everything that I wanted to touch. I will not go into detail, but submit my statement into the record.

I would like to say that we are the only industrial country in the world without a national health policy. Canada has one, as do all the other Western European nations.

We are the only country, I will repeat it again so that people will hear it very clearly: an industrial nation that has no health policy for its people is a shame and a disgrace. I am very grateful and I applaud you, Chairman Pepper, for your devotion and leadership on this issue and also for recognizing that we in California have really pioneered many health care programs and perhaps we can learn from our experiences here, some of the things that need to be done nationally.

I am very pleased to see our great Lieutenant Governor here, Leo McCarthy. He's done a magnificent job and I know how he feels about this particular issue.

I would like to also enter into the record a statement by the California Conference of Catholic Charities Directors, if I may.

Thank you.

Mr. PEPPER. Thank you very much, Mrs. Burton, for your excellent statement. We are so grateful, as I told you before, for your being here.

[Prepared statement of Representative Sala Burton follows:]

PREPARED STATEMENT OF REPRESENTATIVE SALA BURTON

Mr. Chairman: I would like to congratulate you for holding these hearings.

My hope is that the testimony we hear today will help to illustrate some of the difficulties in our present system of health care and will lead to efforts to correct the deficiencies which currently exist.

We are all familiar with the great and escalating cost of medical care. This problem is particularly critical for the elderly—but it is by no means limited to them.

The fact is that those in need of long-term health care—whether young or old—too often face devastating medical bills and even bankruptcy.

The virtual absence of public or private assistance—except under Medicaid—for care for the chronically ill can lead, in extreme cases, to the separation of families or to the institutionalization of those who might better—and less expensively—be cared for at home.

The financial difficulties of the Medicare system will ultimately propel us to a resolution of these problems for the elderly and, hopefully, for all our people.

Current health care systems often limit or prohibit payment for many valuable preventative care services that might prevent costly hospitalization—services such as hearing, dental and eye examinations, regular check-ups and other screening services.

As a nation we must confront the inadequacies of our health care system. We must act more vigorously to prevent illness as well as to treat it, and to encourage whenever possible care in the home rather than in hospitals or other institutions. And we must accept responsibility for necessary care for the chronically ill.

Ultimately such a restructured system will provide not only better health care but also less costly health care.

I would like to applaud Chairman Pepper for his devotion and leadership on this issue, and for his recognition of California's pioneering efforts to protect the health and well-being of our citizens. I welcome our witnesses and look forward to hearing their testimony.

Mr. PEPPER. Now, I would like us to hear from another distinguished member of your delegation in the Congress, Mrs. Barbara Boxer.

STATEMENT OF REPRESENTATIVE BARBARA BOXER

Mrs. BOXER. Thank you so much, Mr. Chairman.

I think I need a microphone.

Mr. PEPPER. I am sorry.

Mrs. BOXER. I am very low tech.

Mr. Chairman, I cannot thank you enough for coming here today and being with us in the San Francisco area.

You are a hero to so many people all across this country.

I remember bringing my mother to Washington to see me in my new job and introducing her to many of my colleagues, but nothing thrilled her so much as meeting you, Mr. Chairman. I think you remember that and it's because you are such an advocate for the aging of this country and you're such a great role model for us all.

So thank you for being here and sharing that special sparkle that you have.

And thank you as well to our great Lieutenant Governor, Leo McCarthy, and our great State representative that we have with us today.

Mr. Chairman, it is good news that Americans are living longer, but we're not necessarily living longer in perfect health or with economic security or with the loving care that all human beings need.

The golden years for many Americans are growing tarnished, sometimes with loneliness and poverty and lack of long-term care and loss of dignity.

There is no other issue, Mr. Chairman, that cries out for redress such as this one.

The other day we learned about a gentleman who had been in a nursing home in California for some 14 years and this story was an incredible one. He had been paying with his own funds for this nursing home care.

When he ran out of funds, he had to go on medicare, Mr. Chairman, and the nursing home where he had been for 14 years said, "Sorry, sir, we don't take medicaid patients." And they proceeded to try to remove him from this nursing home in which he had been for 14 years.

Now, I ask you if this is an America of compassion?

Is this an America that we can be proud of?

I think that when we hear of examples like this we don't feel proud. We don't feel good about our country. It is a shame upon this country that people must lose their last dime before getting any assurance of long-term care and I know with your great leadership, Mr. Chairman, you will take this issue across this great Nation and we will come up with solutions, and today, as we listen to the witnesses and our great Lieutenant Governor, I think we've made a start.

Thank you very much.

Mr. PEPPER. Thank you very much, Mrs. Boxer. We appreciate your excellent statement.

Now, we'll be pleased to hear from the distinguished chairwoman of the Aging Committee of your assembly, Mrs. Jean Moorhead.

STATEMENT OF JEAN M. MOORHEAD, CHAIRWOMAN, ASSEMBLY COMMITTEE ON AGING AND LONG-TERM CARE, CALIFORNIA LEGISLATURE

Mrs. MOORHEAD. Mr. Chairman, thank you very much for the honor of being here with you today and your distinguished colleagues and my own colleagues from the State.

As chair of the Committee on Aging and Long-Term Care, I've had hearings during the late fall as you have had. Two out of those

four hearings were on Alzheimer's disease and I share with you the great concern that we are doing nothing with regard to research with a disease that affects one out of three families in the United States with most likely far more.

We in California are about to change our licensing laws so that we can have the day-care facilities that are necessary, so that we can have the necessary secured facilities.

The testimony that we've heard is that we've gone to opening up all facilities and an Alzheimer's patient needs a secured environment, one that will make them be independent for as long as possible.

I share those concerns with you at the State level where we will be introducing legislation to that effect.

What we need is the help and coordination of the Congress to accomplish what we want to accomplish in the State of California.

I also discovered in the hearings that I have held—in this State, at least, that this society puts a greater priority in the care of our animals than our elderly.

I discovered that a zookeeper, for example, makes $8 an hour, because we care about our animals, but a nurse assistant working in a nursing home makes $3.50 and yet we expect that nurse's assistant to include comprehensive and complete care.

We've got to bring about change and we do that by getting people involved. With your leadership, we can.

I'm delighted to be here. Thank you very much.

[The prepared statement of Mrs. Moorhead follows:]

PREPARED STATEMENT OF JEAN M. MOORHEAD, CHAIRWOMAN, ASSEMBLY COMMITTEE ON AGING AND LONG-TERM CARE, CALIFORNIA LEGISLATURE

I am deeply honored and extremely delighted to share the dais with "Senator" Pepper, who is perhaps the most eloquent voice in Congress, speaking out for the concerns of the elderly; with Congressman Roybal, the Chairman of the Committee of Aging, with Representatives of our California congressional delegation, Congresswoman Sala Burton and Congresswoman Barbara Boxer, with Congresswoman Mary Oakar, our Lt. Governor Leo McCarthy, and our speaker of the assembly, Willie L. Brown, Jr.

"Long-term care," or chronic health care, is the most burdensome concern among the elderly, the functionally-impaired, the chronically-ill, and their families. When the California senior legislature convened this past October, seven out of ten proposals sent to the regular legislature were concerned with health care. Yet, the care that is available tends to be both inappropriate and extremely costly. The tragic reality is that today's health care is much more expensive than it needs to be and is also non-responsive to the needs of the patient and the patient's family. Consequently, the elderly and disabled are not only given poor quality care but are stripped of their dignity and independence as well. They are literally "warehoused" until death.

The need for the development, expansion and promotion of more community based, home-oriented, and preventive health care alternatives should be the most important objective for government at all levels, and for the health care industry as well.

Over the last decade, we have seen the establishment of innumerable pilot programs to demonstrate the effectiveness of these community-based and home-oriented alternative modes of care. Many of these pilot programs have proven their effectiveness. I believe it is now time to make a clear and unwavering commitment to expanding and mainstreaming these programs so that all elderly and functionally impaired persons may have access to effective and responsible care.

Failure to move in this direction will only prove to be penny-wise and pound-foolish. In view of this, it is quite disconcerting to hear of proposals by the present administration in Washington to scale-down the current medicare system. In spite of

its considerable problems, the medicare system should be retained and expanded to cover adult day health care and more home health services.

In addition to expanding proven programs and implementing proven concepts, we must also expand the body of knowledge and address the impacts of Alzheimer's disease and disorders related to aging. I have heard from hundred of individuals throughout the State of California of the living hell that both victims and family members endure as a result of Alzheimer's disease. 2.5 million persons are affected by this tragic disease, yet we do not know what causes it, how to cure it, or even how to treat its symptoms.

Finally, we must improve the training (and, in some cases, the pay) of those in the health professions so that they are prepared to treat long-term illnesses. At the present time, many zoo-keepers are better trained and better paid than primary care-givers in nursing homes.

We have a long way to go. This Hearing and your testimony will hopefully move us in the right direction.

"Senator" Pepper's staff has expended considerable effort in planning this hearing and lined up some very expert witnesses. So, I look forward to hearing from you and learning from what you have to share with us.

Thank you.

Mr. PEPPER. Thank you very much, Ms. Moorhead. We're delighted to have your excellent statement and I'm so grateful to have those two distinguished representatives of your legislature, because we must work together at the Federal and the State level if we're going to accomplish what we should for the elderly of this country.

Now I'm very pleased to introduce another distinguished citizen of your great State, chairman of the Subcommittee on Aging of the State Senate of California, a man who has a long and brilliant record of service to the elderly, chairman of the Subcommittee on Aging of the Senate, Hon. Henry Mello.

STATEMENT OF HENRY MELLO, CHAIRMAN, CALIFORNIA SENATE SUBCOMMITTEE ON AGING

Mr. MELLO. Thank you very much, Congressman, and I'm certainly pleased to welcome you here to California and thank you for the great leadership that you have provided in Congress.

We are truly indebted to this fine gentleman, whose excellent leadership on the important issues affecting our elderly we acknowledge.

I will just summarize my statement because it will be there to present for your record.

I would like the committee to know that what we are attempting to do in California is to develop programs for keeping people in their homes for as long as possible and providing services to defer the institutionalization of our elderly. One of our programs that is working quite well is the adult day health care program which I have authored for the last 4 or 5 years to get startup funds. We now have about 30 centers operating in California. This year we have 85 new applications by agencies for new adult day health care centers throughout the State.

The second program is the multipurpose senior services program that our distinguished Lieutenant Governor, Leo McCarthy, started as a pilot project.

The project has now turned into an ongoing program and will continue to be funded. It provides services for purposes that are in imminent risk of institutionalization. Without this great program, close to 100 percent of the clients would be, of course, in institutions.

Two other of my bills I think are very important, because in order to keep people in their homes, you must have housing for them. One of my bills is shared housing where we try to match up the needs of senior citizens and place them together in sharing the cost of housing.

We will now be serving over 6,000 new clients this year because of the expansion of the shared housing program.

Another one of my pieces of legislation is the granny housing bill a term and practice which was started in Australia and is now a law in California. It allows the placement of a second unit on a single-family lot. Many persons—frequently elderly are living in an underutilized home. By a granny housing concept, they can move in the smaller home and lease out the larger home for family income.

Another breakthrough that's happening in California—and again I want to thank our Lieutenant Governor for his leadership and that is the Little Hoover Commission report on nursing homes.

There are some shocking revelations throughout the State of California about the care of the elderly and avoidable institutionalization of the elderly. One of the most blatant practices that is being used is when a person is a private-paying patient and they run out of funds and have to convert to medical, and they are given notice of eviction by the nursing home.

I think it is very cruel to evict someone when they can no longer pay private fees. So I'm introducing a whole package of bills that will call for segmented surveys of the nursing homes and ways in which we can bring them up to the quality of care that we in California hope for and desire.

The whole question of respite care is also important, because in order to provide much needed care for our senior citizens, we must provide hospice care and respite care and a variety of programs.

Last, of course, is that of nutrition.

It's shocking to see that in California, our present administration blue-penciled over $2 million from the budget for senior nutrition when we have 4,000 people a day being turned away from nutrition sites.

We have 9,000 people on the waiting list for home-delivered meals; yet we are not providing the adequate nutrition, Congressman, and I know you agree that this is one of the really important things that we need for our people: proper nutrition and proper feeding.

So, those are my remarks, Congressman, and again I want to thank you for having this hearing in San Francisco where we can come here and tell you a little bit about California's problems and our solutions and our desire to continue to work with you in this whole field of helping the aging.

Thank you very much.

[The prepared statement of Mr. Mello follows:]

PREPARED STATEMENT OF SENATOR HENRY J. MELLO, CHAIRMAN, CALIFORNIA SENATE SUBCOMMITTEE ON AGING

I am pleased at this opportunity to join with Congressman Claude Pepper and other elected officials of the Federal and State government for today's hearing on long term care. It is a great pleasure to be here with Congressman Pepper, who has

exercised such a magnificent leadership role on behalf of older people throughout the United States. I had the pleasure of meeting with him in Washington some months ago to discuss, among other matters, our common concern that older Californians be represented in appropriate numbers at the conventions of both the Democratic and Republican parties. I am continuing to pursue that issue here in California.

I have been consistently impressed with the great importance older persons give to remaining in independent living. Quite understandably, nothing is dreaded more than unnecessary institutionalization.

Let me first emphasize that in seeking the goal of independent living for California's elders, I have given special attention to the Multipurpose Senior Services Program (MSSP) approach within which Adult Day Health Care is a key element. I have also pressed forward with innovative programs in housing—recognizing the important role of decent shelter for older persons. I am also exploring the need for respite for family members and for broadening the availability of senior nutrition.

Let me review some of my recent legislation bearing on these topics: SB 134—Adult Day Health Care; SB 722—Multipurpose Senior Services Program; and SB 19—Shared Housing.

SB 134 (CH. 1208-1983), the Adult Day Health Care bill, provides $350,000 in start-up funds for Adult Day Health Care centers. It was signed by the Governor September 28, and became effective immediately.

There are currently 29 licensed Adult Day Health Care centers in 14 counties in California. I am pleased to report to you that as of the end of November, 84 letters of interest had been received from 37 counties requesting over $3.6 million in start-up funds. This clearly indicates the tremendous need for continuation and expansion of Adult Day Health Care services. I am having a bill drafted now seeking $1 million in added start-up funds for Adult Day Health Care. It is one of my legislative priorities for 1984—as it is of the California Senior Legislature.

As indicated, Adult Day Health Care is an essential element in the Multipurpose Senior Services Program (MSSP) approach. SB 722 changed the Multipurpose Senior Services Project from a demonstration project to an ongoing program. The typical MSSP client is a low-income, 78-year-old widow who lives alone and has serious health complications. Approximately 30 percent of the MSSP caseload is comprised of clients at imminent risk of nursing home care. This population especially will be served by SB 722.

In the best of circumstances, some frail elderly will face appropriate nursing home placement. I chaired a hearing of the Senate Subcommittee on Aging recently to review a series of major recommendations for nursing home reform developed by the Little Hoover Commission with the assistance of an advisory committee chaired by Lt. Governor Leo McCarthy. I am having legislation prepared to implement those recommendations.

In respect to housing, I would like to mention Senior Citizens' Shared Housing and Second Unit Housing as important programs to assist keeping older people in California in independent living. SB 19 (CH. 1307-1983) was signed into law on September 30, and became effective immediately. It establishes a permanent senior citizens' shared housing program.

SB 19 appropriates $300,000 from the Rental Housing Construction Fund and is expected to assist 6,000 persons with shared housing arrangements. Some of these persons may be other than seniors because of a new intergenerational feature in the bill. There are currently over 60 shared housing organizations statewide.

SB 1534 (CH. 1440-1982) is a follow-up to my "Granny Housing" bill, (SB 1160, CH. 887-1981). It encourages local governments to allow creation of a second unit in an existing residence. Second units represent a viable means of increasing our rental housing stock, while maintaining the integrity of our single-family neighborhoods. Second units provide homeowners with declining incomes, such as seniors, with a way to remain in their home because of the additional income and security provided.

A specific aspect of long term care that attention is called for at both the State and Federal levels is the role of families in providing long term care to disabled and elderly adults. Families provide 80 percent of all medically related and personal care to chronically ill older persons in their home. This committee will hear first-hand today about the overwhelming responsibilities that can accompany caring for an ailing spouse, parent or adult child on a full-time basis.

Public policy must recognize the needs and the dedication of family caregivers, and permit and encourage provision of respite care services. By allowing these individuals some personal time away from their caregiving responsibilities, we can enhance their ability to continue to provide quality care and prevent the physical and

emotional deterioration that might otherwise occur. Without respite services, many family members may feel compelled to institutionalize their loved one, and may even require hospitalization or institutional care themselves. These families save the public millions of dollars a year in social services and institutional costs. It is sound public policy to support and encourage their efforts.

I am currently examining the whole question of respite care services in California in order to identify roadblocks that exist and to determine what positive steps might be taken to build our long term care policy in respect to the vital role families are playing. It would be helpful if this Subcommittee undertook to actively pursue changes in Federal law in this area, notably in Medicare and Medicaid. We need to also involve private insurance carriers in long term care coverage.

As we all recognize, there is a close interrelationship among the varied programs that are aimed at keeping older people in independent living. I have discussed aspects of health care and housing. Clearly, senior nutrition is another vital component. I am committed to broadening the availability of senior nutrition programs in California to help satisfy a substantial unmet need.

I am pleased to report that through close contact with Congressman Leon Panetta, Chairman of the Subcommittee on Domestic Marketing and Nutrition of the House Committee on Agriculture, I and others of the Senate leadership have made it possible that surplus food commodities, valued at $2.8 million that are available through the Federal Emergency Jobs Act, are now being redirected to senior nutrition sites in California in order to achieve their full utilization.

Nutrition, housing and Adult Day Health Care are all vital components in a system of long term care such as we are striving to develop in California through AB 2860, authored by then-Assemblyman now-Senator Art Torres and of which I was principal Senate co-author. The objective of AB 2860 is the linking together of these and other health, social and personal care programs into a system. The Governor has established an Interim Office of Long Term Care to devise an administrative plan for implementation, which will consolidate into a new Department of Aging and Long Term Care the programs presently located in 4 state agencies and 19 other governmental units.

We expect the administrative action plan to be submitted to the Legislature by the first of January, 1984. There are indications that difficulties exist in implementing AB 2860 which can only be resolved with the cooperation of the Federal government.

When we receive the Governor's report detailing specific problems that need to be addressed, such as certain waivers, we will be asking the assistance of you, Congressman Pepper, and the Subcommittee.

Thank you for this opportunity to be with you today. I look forward to working closely with you on the many problems facing elderly persons.

Compliments of Senator Henry Mello
Chairman, Senate Subcommittee on Aging
17th Senatorial District

HISTORICAL SEQUENCE OF EVENTS IN LONG TERM CARE IN CALIFORNIA

1971 - 1983

Year	Issue Identification: Policy Reports/Studies	Hearings	Legislation	Programs
1971	Nursing Homes: A series of articles appearing in the San Diego Union expose deplorable conditions in some Nursing Homes in San Diego County.		SR 221 calls for an investigation of nursing homes. ACR 48 establishes the Joint Committee on Aging. Assemblyman Leo T. McCarthy, Chair.	
1972		Joint Committee on Aging, "Nursing Homes and Alternative Care,": (1) February 18, 1972 Long Beach (2) March 19, 1972 San Diego (3) December 12, 1972 San Francisco		On Lok Senior Health Services (San Francisco) gets AoA grant to test day health care as an alternative to institutional care.
1973	"Supportive Personal Services for the Aged" prepared for Earl Brian, M.D., Secretary, Health and Welfare Agency. Purpose: To establish a program of supportive services for aged which will improve cost effectiveness and allow aged to remain in homes and communities as long as possible.	(4) January 23, 1973 Sacramento (5) January 30, 1973 Sacramento Joint Committee on Aging, "Senior Day Centers--A Multipurpose Approach to Self-Maintenance for the Older Adult." December 3, Santa Cruz.	As a result of nursing home hearings, eight bills are introduced. Three become law. AB 1600, Chapter 1057, Long Term Care Health, Safety and Security Act of 1973, revises nursing home inspection procedures and sanctions for non-compliance. AB 1601, Chapter 924. AB 1607, Chapter 1058, Pilot Project in Preventive Health Care.	Adult Protective Services Day Health Care Program funded. (San Diego)

Year	Issue Identification: Policy Reports/Studies	Hearings	Legislation	Programs
1974		Joint Committee on Aging, "Health Care Services for Rural Elderly and Problems Confronting Elderly Ethnic Groups in Rural Areas." Merced, October 23.		Senior Health Day Center, Sacramento, receives a one-year federal grant (OAA, Title IV) through California Department of Aging. September. On Lok Senior Health Services contracts with State Department of Health to test adult day health care and receive Medi-Cal reimbursement. Section 1115, Title XI, Social Security Act waivers are obtained from DHEW (1974-1977). December.
1975			AB 1810, Chapter 1350, introduced by Leo McCarthy. Bill directs Health and Welfare Agency to establish criteria and adopt regulations by which multi-purpose senior centers provide specified services to enable impaired adults to remain in community. Authorizes adult day health care pilot projects funded by Medi-Cal and gives necessary contract powers to Department of Health.	Section 222 (P.L. 92-603) grant to San Francisco Home Health Agency to test in-home supportive services and day health services at three sites: Mt. Zion, Garden Sullivan and Franklin Hospitals. Project funded for 18 months and extended to April, 1977. July.

Year	Issue Identification: Policy Reports/Studies	Hearings	Legislation	Programs
1976	Department of Health Director, Jerome Lackner, M.D., establishes Adult Day Health Care Work Group to establish criteria for foundation of additional pilot projects and licensing and certification regulations for statewide program.	Commission on Aging, "Alternative Health Systems and Alternatives to Institutional Care,": (1) April 22, Los Angeles (2) May 6, Delano (3) May 19, San Francisco (4) June 22, Jackson (5) June 23, Sacramento Assembly Special Subcommittee on Aging, "Adult Day Health Services--Pilot Project or Permanent Program?" Long Beach, October 8. Result: Commitment for ADHC legislation.		
1977	Auditor General's Report: "Cost Does Not Equal Care: Overview and Medi-Cal Reimbursements for Skilled Nursing Home Care, Part I of III." January 17. Auditor General's Report: "Care vs. Regulations: Enforcing Quality of Care Nursing Home Patients, Part II of III." October 7.		Governor Edmund G. Brown signs into law: (1) AB 1611, the California Adult Day Health Care Act; (2) AB 998, Multi-Purpose Senior Services Act; (5) AB 1612, Start-up Grants for ADHC Centers.	Second Section 1115 enables contracts with Adult Protective Services, San Diego and Senior Day Health Center, Sacramento, as ADHC pilots. Third Section 1115, adds Garden Sullivan, Mt. Zion. November. - continued -

Year	Issue Identification: Policy Reports/Studies	Hearings	Legislation	Programs
1977 cont.	Department of Health Report: "Services for the Elderly." Study of services for the elderly, emphasis on LTC, and the introduction of Adult Day Health Care legislation. Auditor General's Report: "Continuum of Services for the Elderly: Lack of a Planned Integrated System of Services for the Elderly, Part III of III." December 30.			
1978			AB 1611, Adult Day Health Care Act, goes into effect.	Adult Day Health Care Medi-Cal and Licensing Regulations implemented. July. Project Open, Mt. Zion Consortium, receives Medicare Waiver.
1979		Joint Hearing of the Assembly Committees on Health and Welfare; Aging, "Adult Day Health Care Oversight." September 27. Joint Hearing of the U.S. Special Committee and California Assembly Committee on Aging, "Medicare, A Broken Promise?" San Diego. October 24. "Supplemental Medicare Insurance: The California Experience." Seaside. December 14.		On Lok Health Service Medicare Waiver, Section 222 project, testing comprehensive health and social services to establish data base for prospective budget, capitation. HSSP Section 1115, waiver application approved (conditional).

Year	Issue Identification: Policy Reports/Studies	Hearings	Legislation	Programs
1980	Assembly Office of Research, "Facilitating Access to Skilled Nursing Facilities for Indigent Patients," February. Department of Finance, "Service Integration for the Elderly," Phase II. March. Office of Statewide Health Planning, "California State Health Plan, 1980-1985." Senator Nolle urges Governor Brown to support state participation in the National LTC System Development Program. March. With support of Governor Brown, Health and Welfare Agency receives LTC System Development Grant. October. Long Term Care Advisory Committee Report - Office of External Affairs, Department of Health. December. Health Policy Forum Report, Medi-Cal Subcommittee recommends a Long Term Care Proposal - Department of Aging and Long Term Care. December	Assembly Committee on Aging, "Adult Day Health." Leisure World. March 7.	Assembly Committee on Aging becomes a standing committee. AB 2687 authorizes Department of Rehabilitation to do feasibility study for comprehensive Independent Living Centers. AB 2992 - $500,000 appropriation for start-up grants for new ADHC centers. AB 2975 - Older Californians Act becomes law. SB 1883, Department of Health Services Study, Level of Care, Costs and Quality of Care in Nursing Homes. Senate establishes a Special Subcommittee on Aging.	MSSP Section 1115 waiver, full approval, DHHS, sites begin building caseload. April.

Year	Issue Identification/ Policy Reports/Studies	Hearings	Legislation	Programs
1981	California Health Facilities Commission Report. Department of Finance first volume in series "Social Services for the Aging, the Present, the Future." July. Joint Legislative Budget Committee approves Section 28 waiver for LTC System Development Grant. Project Team assembled, work begins on LTC System Development Grant. Long Term Care Systems Development Project releases their report. Recommend consolidation of LTC programs and funds from Medi-Cal, Title XX of the Social Security Act and Title III of Older Americans Act. December. StateHouse Conference on Aging meets. LTC one of priority issues. April.	Assembly Committee on Aging, "Nursing Home Care," July 27, Torrence; October 9, Sacramento Joint Hearings, The Future of Long Term Care. Assembly Health and Assembly Aging Committees, October 14, Los Angeles; October 20, San Francisco. Long Term Care Systems Development Project, "Public Forums on Long Term Care and Aging: Minority and Rural Perspectives." (1) July 11, Oakland (2) July 18, Orange Grove (3) July 25, San Diego (4) July 29, Yreka Senate Subcommittee on Aging, "Housing for Seniors," Monterey, October 7, 1981. Senate Subcommittee on Aging, "Long Term Care/Adult Day Health Care," Santa Cruz, November 13, 1981.	SB 850, CH. 478 - $250,000 start-up funds for new ADHC Centers. AB 1600 - Long Term Care Bill, March. (A framework bill for discussion.) Senior Legislature meets. Top priority goes to a LTC system. July. SB 633, passed Legislature. Changes made in IHSS. SB 1160, CH. 887, Granny Housing. SB 1228, CH. 1035 Shared Housing Pilot Project	

YEAR	Issue Identification: Policy Reports/Studies	Hearings	Legislation	Programs
1982	Long Term Care Inventory of California. March	Senate Subcommittee on Aging, "Alternatives to Institutionalization," November 15, Salinas, November 17, San Luis Obispo.	AB 2860, CH. 1453 - The California Long Term Care Act.	Senior Care Action Network (SCAN) Long Beach, selected to be one of the field test sites in a Social/ Health Maintenance Organization federal demonstration project being conducted by a consortium of three universities: Boston; Brandeis and the Massachusetts Institute of Technology. February.
1983	Conference on Community Based Long Term Care, San Francisco, January 21, 1983, (Sponsored jointly by Legislature)		SB 134 - Adult Day Health Care SB 722, CH. 306 - MSSP SB 19 - Shared Housing	

Mr. PEPPER. Senator Mello, thank you.

We are pleased this morning to have represented here on this podium, a representative of the Congress of the United States, a representative of the Senate and the House of Representatives of your assembly. So we have cooperation at the Federal, State, and local level. And now I'm pleased very much to introduce again, for a statement that she will make, Joyce Ream, who is the director of the San Francisco City and County Commission on Aging.

Ms. Ream, we're pleased to have you here.

STATEMENT OF JOYCE REAM, DIRECTOR, SAN FRANCISCO CITY AND COUNTY COMMISSION ON THE AGING

Ms. REAM. Thank you very much, honorable chairman and members of the panel and Hon. Lieutenant Governor.

I bring you warm greetings from the mayor of San Francisco and the San Francisco Commission on Aging.

A little while later in the program Dr. Mervin Silverman from the Department of Public Health will be entering detailed testimony from Mayor Feinstein.

I would like at this point to reiterate both the concerns of, and the opportunities for serving seniors, both of which I think are exemplified in San Francisco.

We think you honor us by having a hearing on this issue here. Long-term care is of particular importance for San Francisco, since 137,000 of our citizens or over 20 percent of the population of San Francisco is over the age of 60.

We have grappled with the issue of long-term care. I think one of the encouraging factors about San Francisco is that we have had extensive cooperation between the Department of Public Health and the Commission on Aging, between public and private agencies, and with foundations in terms of also providing financial funding.

The continuum of cooperation that has occurred in this city is one of the delights, so far as I'm concerned, of working with this issue.

Yet as we view the issues of adult pay health and long-term care we all recognize that we are not dealing with these programs in isolation, that there is an enormous Federal impact and State impact on what it is that we are able to do.

To the degree that we can hear both from citizens here today, as well as from the assembled public officials, I think we'll all be in a position to be able to see what we have to work with, and how we can coordinate that better to provide a better life for seniors, in San Francisco, in California, and in the Nation.

Thank you very much for having me here today.

I plan to listen with great interest.

Mr. PEPPER. Thank you very much, Ms. Ream.

Before we begin now with the rest of the program, I want publicly to express for all of us, our appreciation to Chief Judge Peckham who made possible our use of this ceremonial courtroom for this hearing. We are grateful to Judge Peckham for that kindness.

Now, we have a great honor and pleasure to introduce one of the outstanding advocates of the elderly in the whole of America, your distinguished Lieutenant Governor.

You know, of course, that he was formerly speaker of your assembly. He's one of the leaders in the public life of this great State.

We know him all over the Nation for his advocacy of causes related to the well-being of the elderly.

I had the privilege and the honor of having breakfast with him this morning and we talked about these matters of mutual interest and concern.

So I'm very pleased to present as our first witness your distinguished Lieutenant Governor, Hon. Leo McCarthy.

We welcome your statement, sir.

STATEMENT OF LEO McCARTHY, LIEUTENANT GOVERNOR, STATE OF CALIFORNIA

Mr. McCARTHY. Thank you, Mr. Chairman, and distinguished members of the panel.

I'm grateful to have this chance to testify.

Mr. Chairman, I wanted to say first of all that those in our line of work don't normally admit to themselves that they have role models that they admire enormously.

You are one for many of us and I'm very grateful for what you have done for four decades and the intensity that you still bring to try to ease the conditions in which many elderly people live in America.

I got into it 20 years ago, less than half the time you've been spending in this field, but it was 10 years ago that we authored nursing home reform legislation in California. At that time, frankly, with the help of media exposes, good, old-fashioned digging journalism, we found out just how many abuses were being committed in this State and we authored a number of laws then.

Frankly, they came about because seniors in this State organized and they wanted to send the message to the legislature and to the then Governor that they were not going to tolerate the kind of misery that many Californians were living in in the nursing homes.

Those 10 years have gone by and at the beginning of this year the leadership of the Little Hoover Commission asked me to chair an advisory committee, because they had held some hearings and they found out that, although we had tightened up the inspection program, and although we instituted a penalty system where you didn't have to go through the interminable court action to get a suspension or revocation of a license to run a nursing home, you still had a better method. You could impose penalties and we still had many abuses going on in the State of California.

We have 100,000 elderly Californians in nursing homes; frankly, over a third of them shouldn't be there. You're addressing those issues in the Congress, but the fact is we haven't provided for alternatives to full institutional care.

So we tried through public hearings and through careful, documented research to examine the conditions that we have today in nursing homes in this State.

We came forward with 80 recommendations, Mr. Chairman and members of the panel, and we're going to put those in legislation to be introduced in January.

Sitting on that advisory committee were representatives of Senator Mello and Assemblywoman Moorhead who were quite serious about pushing forward with those recommendations and who were well aware of the fact that the nursing home industry in the State of California, which has contributed more than $300,000 in campaign contributions to members of the legislature in just the past 3 years, is going to fight us on many of those recommendations, because they don't like them and they think that they can quietly prevail in the proceedings, perhaps late at night, of some committee meetings when we may struggle for a quorum and win on a number of the active provisions.

Well, the seniors of this State are not going to let that happen, Mr. Chairman.

Yesterday in Sacramento we had a meeting of a coalition of senior leaders from around this State. These same two State legislators had representatives there.

We heard what happened and we understand that seniors once more in California are not going to tolerate what's happening in institutional care, because there are too many bad examples of what is going on and frankly, they are tired of being had.

They're tired of patronizing statements, pats on the head, if you will, including those from a number of people in both parties who pretend that they are friends of the seniors and then fold when the rather substantial economic forces that profit from nursing homes in this State get involved in the bill process in the legislature.

They're not going to let that happen.

They're going to do a number of things to prevent it from happening.

One of the things they are going to do, Mr. Chairman, is to circulate petitions in this State and they're going to gather as many signatures as would be required to qualify a constitutional amendment in the State of California.

But they're not going to put that on the ballot, because these seniors were raised in the tradition of representative government and they want to have faith and trust in our Governor and in the membership of the legislature.

But they're going to give a demonstration that if they were going to put an initiative on the ballot, they could easily qualify it.

So they are going to gather up over half a million signatures and they're going to address the legislature in respectful terms, and the Governor of this State, and they're going to ask for adoption of these recommendations.

Two thirds of these 80 recommendations require statutory change. About one third require administrative action.

They're very basic kinds of things:

Establishing a consumer information system, if you will. Los Angeles County did this on their own initiative. They get a 100 calls a week and at least they're in a position to have a do-not-refer list to make sure that family members do not send their parents or grandparents to nursing homes which have horrible records, which

cut corners, and are not sensitive to the elderly and disabled people in their midst.

Then we're going to recommend that where you have good witnesses that are fearful of intimidation: employees of nursing homes or family members, who are afraid of what will happen to their families, that when we have good, solid, substantial evidence, that we get our department of health services people in there very quickly.

Now, there's a lapse of time, and maybe there would be a way to correct some of the bad things that are happening but we don't get to address the abuses that are going on.

We have enormous space problems in this State. There is tremendous pressure because of the lack of alternatives to full-time institutional care.

We have 95 percent occupancy in the nursing homes in this State. We can't even find beds for medical patients in the bay area and many other parts of the State.

Well, we could go on and on with a series of recommendations. Senator Mello referred to one which is an outrageous kind of action, that if you enter a nursing home privately funded and then your funds expire after 6 months or a year, even if you're eligible for MediCal in this State—you can't then use those funds.

You're thrown out of the nursing home because they don't want to deal with MediCal patients.

Now, there is something basically wrong with that kind of value system that allows that sort of action to occur again and again, hundreds of times in this State.

Mr. Chairman, we are trying very desperately to establish alternative methods so that we don't have this pressure to keep committing people to the anonymity of institutional care nursing homes.

I want to insert here that there are some nursing homes in this State that go out of their way to run good operations. Unfortunately, there are too many that view this solely as a profitmaking kind of operation.

Now, maybe we thought that we were doing the right thing in the Federal Government in the mid-sixties when we got this going and I think we have improved the lot of the elderly.

We still have allowed an institutional pattern to develop which unfortunately permits a lot of abuse and neglect of elderly people.

You're trying to address this in Congress when you say let's develop some kind of alternatives.

Senator Mello sponsored the adult day health center programs in this State. He struggled in just the last 2 years, passed bills for $1 million appropriations and the Governor slashed them $250,000 and $350,000 in 2 successive years.

We thought 5 years ago we could get 300 adult health centers established. We are at 28 and struggling to increase it.

We know it costs a lot more money for institutional care. We know from the MSSP programs that the Senator referred to, multiservice senior projects which were jointly funded by the Federal Government, that we save at least $3,000 per patient over the year over the costs of what it would take to put those high-risk elderly into full-time nursing home care.

We know if we keep them independent and, not too incidentally, help them keep their dignity, prevent them from losing all self-esteem, we save money.

So we can make the argument on economic grounds.

Those MSSP programs went into eight communities in this State, rural and urban, different ethnic mixes, and we know consistently that we have the technical and financial data to prove that we can have alternative care in the State of California.

Mr. Chairman, we desperately need your help in Washington to try to push these through. If we had 20 Claude Peppers in the Congress of the United States, we'd make things happen.

We'd bring the Reagan administration around so that the changes would occur.

Well, they're really not too complicated. We have to try and merge medical and medicare funding methods. It's not sensible to pay extensively for medicare treatment in acute-care hospitals and then not follow up with some kind of continuum of care and make sure that people don't go back into the sort of health conditions that would once again require acute care, at very expensive acute care hospital.

We've got to merge the use of those two funds and then we've got to amend the medicare law and indeed the medical law more generously to try to allow the financing of alternative care.

The day-care centers that Senator Mello has pushed.

The MSSP-type programs.

Anything that will give the elderly some modest health check-ups.

Help them with the daily needs they have; with banking, and shopping, and give them some sort of social contact.

That simple combination is going to keep even high-risk elderly out of institutional care.

I don't think the commonsense of this would be missed by anybody if only we can get their attention.

I think you're going to get their attention. There are a lot of people that don't know what you're doing throughout this country, but more are finding out and I just hope you keep continuing in the intensity you've brought to this field on into the indefinite future.

I personally thank you very much and thank you for allowing me to give this testimony.

Mr. PEPPER. Thank you, Mr. McCarthy, and I want to thank you for your expert statement. We thank you for what you're doing, the fact that you're trying, with your colleagues here, to make life better for the senior citizens of California.

I imagine that you have, as we do in Florida, a large percentage of your population who are over 65 years of age.

When I was born in 1900, only 5 percent of the people of this Nation were over 65 years of age. Now, 11 percent—over twice as many, percentage wise, are over 65 years of age.

I'm talking about 65 years now, not 60, or 55 years, but 65.

The fastest growing segment of our citizenship percentage wise, is people over 85. I hope that I make it 2 more years, because then I'll get within that 85-and-over group that is supposed to live a long time.

Now, what are we going to do? Are we going to neglect the needs of that large percentage of our population? Are we going to deny them a right to work, for example, to keep on working if they are competent and responsible in their jobs?

Or are we going to make them victims of welfare in order to survive?

We see that we have a serious need to order our society and to construct our programs to help those people who I believe are the most deserving in our citizenship, because they've been here the longest, they have done the most for our country.

They are generally the fathers and mothers of the dominant generation. In war they wore our country's uniform. In peace, they've borne the burden of the economy.

They've held up the standards of patriotism, religion, morality, and decency. I call the senior citizens the VIP's, the very important people of this country. And today they are not receiving the medical care that they should have.

I would hate to think that America is so lacking in compassion and concern that Americans are permitted to die before their time because they can't afford the medical care that might prolong their lives a little bit.

And we don't think enough of them, in gratitude for what they've done, to try and make their last part of a long journey as pleasant, as healthy, and happy as can be, and give them an opportunity to remain positive forces in our country and in our society.

Yet we know, for example, that drugs that are taken in the home by senior citizens who are on medicare, although prescribed by a doctor, are not covered by medicare.

We know that there is no dental care provided under medicare.

We know that there are no hearing aids provided under medicare.

There are no eyeglasses provided.

There is no preventive care given. Even if you could have a test of your blood pressure, find that it was high, have it treated, and avoid a stroke, and all the incidental expense that would follow that stroke, even that desirability doesn't mean that medicare is going to cover it.

They tell me it costs $100 down home to go into a doctor's office and just get a simple test of your blood pressure.

So medicare does not give preventive care. It gives relatively little care in the home where many people would prefer to have it and where it could well be given and be much less expensive than the care in a nursing home or hospital.

I think the Governor told me this morning that probably in California the average cost of nursing-home care would be in the range of $30,000 a year perhaps, and there are a million and a half people in nursing homes. He told me that maybe half of them would not need to be there if they were at some other place where they could be properly cared for.

Now, it may well be, Governor, and I think you and I were agreeing on this—it may well be that the coming financial crisis that is due in about 4 years in respect to medicare may give us, at the Federal, State, and local levels, just the incentive to try to revise this system in a way that will make it less expensive to the Gov-

ernment, less expensive to the patient, and provide more medical care to the patients than they're getting at the present time and that's what we're working toward, is it not?

Mr. McCarthy. That's right.

Mr. Pepper. Well, you've been a very innovative worker in this issue and we want to continue to work with you, Governor, and with the members of the legislature and the city authority toward that end.

Mr. McCarthy. Thank you.

[The prepared statement of Mr. McCarthy follows.]

Prepared Statement of Lt. Gov. Leo McCarthy

On behalf of all Californians, and Senior citizens in particular, I welcome you to our Golden State.

I am pleased to have an opportunity to testify before your Subcommittee because one of my personal priorities, for more than a decade, has been the improvement of our system of health care for the elderly. As a State Assemblyman and Chairman of the Joint Committee on Aging in the early 1970s, I learned of the tragic dilemma faced by thousands of older Californians each year—the dilemma that in order to receive needed services, they had to give up living independently and enter nursing homes. It became clear early on that there had to be alternatives to institutionalized long term care.

Along with a number of my colleagues and fellow Californians, I have worked to develop these alternatives, and I believe that California has established a record of leadership in this area. But the conclusion is also inescapable that much remains to be done, much of our hardest work lies ahead of us.

I believe that today we face two major issues: First the need to continue upgrading of conditions in long-term care facilities, and second, expanding the availability of alternative long-term care programs.

One year ago, Nathan Shapell, Chairman of the Commission on California State Government Organization and Economy—more popularly known as The State Little Hoover Commission—asked me to chair the Commission's Advisory Committee on Nursing Home Reform.

Having authored legislative reforms in the early 1970s because of the deplorable conditions that existed at that time, I was pleased to accept Mr. Shappell's invitation.

Commission hearings late last year had established that ten years later, despite the reforms enacted during the 1970s, we have come almost full circle. Testimony at these hearings made it plain that many of the same problems still exist: problems including poor quality care, the inability of residents and their families to identify and find space in the best care facilities, and, most shocking of all, continued outright physical and mental abuse of residents.

In order to understand the problems that continue to persist in nursing homes, the Advisory Committee was formed to examine the issues and propose solutions. The Committee was comprised of a broad spectrum of the state's population and included representatives from both the public and private sectors.

The Committee worked very hard to gather information, and to listen to the viewpoints of all sides of the issues we were considering. On August 17, 1983, we released our findings and recommendations to the public and the Legislature in a report entitled, "The Bureaucracy of Care."

There are over 80 detailed recommendations in this report. Some call for changes in administrative policy or regulations and others call for new legislation. All are necessary so that facilities which provide good care will not be hurt by the public distrust brought on by those who abuse both the system and those whom they are charged with protecting.

I have brought a summary listing of some of the highlights of those recommendations and will present them to the Committee later. But allow me to point out just a few of the recommendations and the reasons we believe they are so important.

We are calling for the development of a consumer information system which will allow those in need of nursing home care to identify quality facilities, rather than make a choice based upon insufficient information and accompanied by fear and uncertainty.

Los Angeles County presently has a system which receives over a hundred calls a week, and places low-standard nursing homes on its "do not refer" list.

Another problem we believed needed to be addressed was the question of eyewitness evidence as a basis for complaints. We learned of a case where a nursing home employee, horrified by the worsening ulcer on the back of a patient, filed an anonymous complaint. She later learned that there had been no action because the complaint was "unsubstantiated" by other evidence.

We believe that those in nursing homes hardly have the resources to produce courtroom-style evidence for complaints or abuses to which they may be the only witnesses. We urge that eyewitness statements be given credibility unless outweighed by other evidence, that witnesses have appeal rights, and that it should be a criminal offense to retaliate against those who make such complaints. In the case of the patient with the back ulcer, if that nursing home employee could have come forward without fear of being fired, the case might have been followed up much more thoroughly.

Another recommendation is to ease the present limitations on available space in nursing homes. Statewide, their occupancy rates are nearly 95 percent, and in many areas there are long waiting lists. We believe more space is needed.

An example of the need for more space was clearly demonstrated earlier this year when a convalescent center in Northern California announced it was converting to the more lucrative business of drug rehabilitation, and ordered its 110 patients to move out within two months. The center did this despite a desperate shortage of available places for the patients to go. One 81-year-old retired school teacher finally found a place for her 82-year-old sister, who, days later, died of a heart attack. The surviving sister feels it may have been brought on by the shock of the move.

Not only are more nursing homes and more beds needed—for those persons who really need around-the-clock care—but we need the expansion of programs that provide alternatives to nursing homes. Two examples of those alternatives are Adult Day Health Care programs, and the Multi-Purpose Senior Services Project.

Adult Day Health Care (ADHC) in California began as a series of federally funded demonstration projects providing health and social services. Eighty percent of their clients are senior citizens.

California's goal was to have 300 centers statewide by 1982. We fell "somewhat" short of that goal—there are now 26 centers in operation. The main problem, quite simply, is funding.

Last year, a bill authored by Senator Henry Mello, Chairman of the Senate Subcommittee on Aging, requesting a million dollars for start-up funding of new centers, was cut to $250,000. This year, another million-dollar request was slashed to $350,000. Thanks to the persistence of legislators like Senator Mello, we're moving forward; at a terribly slow pace, however.

The Multi-Purpose Senior Services Project (MSSP) is one dear to my heart—while in the legislature, I authored the 1977 law which established this program.

The program provides counseling and support for seniors in institutions or at high risk of being institutionalized, with the objective of enabling them to live independently at home. Nearly two thousand elderly clients are now being helped by MSSPs in California.

There are two hallmarks to these programs: They protect individuals by preserving their independence and sense of self-worth, rather than condemning them to the gray haze of institutionalization, and they are cost-effective. Clients receive Adult Day Health Care at a cost that is over three thousand dollars a year less than nursing home care, MSSP clients attain a public cost saving of over four thousand dollars a year each. This makes budget-cutting of these services an exercise in irony—they don't cost, they save, both money and lives!

I have brought for your review a display which is titled: "Historical Sequence of Events in Long-Term Care in California, 1971-1983." It provides a chronology of events—hearings, legislation and programs—on how long-term care and its alternatives have progressed in our state. I will provide each of you a copy.

When my task force released its nursing home study in Sacramento on August 17, 1983, I called on some of my former colleagues in the legislature to bring action immediately so that these recommendations may become effective as soon as possible.

I am pleased to announce that both Senator Mello and assemblywoman Jean Moorhead, Chairwoman of the Assembly Committee on Aging and Long Term Care, held such hearings earlier this fall.

I am confident that a comprehensive legislative package will be introduced in the January session of the State legislature. And we will work very hard to get that legislation enacted.

I am also very enthusiastic about the response we received at a meeting I held just yesterday in Sacramento. The purpose of the meeting was to form a statewide

coalition of organizations in the aging network in order to develop strategies to make these reforms a reality. It's going to happen!

I know that you're all aware that California has been among the leaders in establishing innovative long-term care programs for the elderly. But we have a long way to go.

As Congressman Pepper so aptly put in in his letter to me, "It is important that we begin now to determine what the federal role might be in structuring a comprehensive continuum of care—a long-term care policy—capable of addressing the preventive, acute and chronic health care needs of our nation's citizens." I agree wholeheartedly with that statement. Let me suggest some of the ways in which the Federal Government can help.

1. MERGE MEDI-CAL AND MEDICARE FUNDS

Presently, there is no method to pool Medi-Cal and Medicare funds to supply monies for alternative care programs. If a patient is chronically ill and gets better under Medicare, that patient is then released from care. There is no follow-up or post-hospital care or services provided to the patient paid for by Medicare. The patient has no alternatives but to (a) pay for all post-hospital care out of his or her own pocket, if the patient is considered to be ineligible for Medi-Cal; or (b) not get any post-hospital care, deteriorate into a chronically ill state again—possibly into an acute state and eventually die.

2. FINANCE ALTERNATIVES THROUGH MEDICARE

Presently, Medicare does not pay for any alternative services such as Adult Day Health care. Medicare pays only for hospitalization or restricted nursing home care, which preliminary studies have already shown to be less cost-effective.

3. PROVIDE PREVENTIVE HEALTH CARE FOR THE AGING

No federal money goes to any preventive health care services for the elderly. The federal government has not shown a willingness to grant waivers or support demonstration services/programs for preventive health. Further, the federal government is reluctant to expand any services (like alternative care or preventive health). It seems to want to provide hospital and nursing home care funding ONLY.

These suggestions must be given serious consideration if we are to reach those objectives with which this Subcommittee is charged. There are a number of other recommendations I could make, but I'm sure they will be covered by others providing testimony here today.

Again, I want to thank you for providing me the opportunity to present testimony on one of the most critical issues facing older Americans today.

Lieutenant Governor
Leo McCarthy
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STATE LITTLE HOOVER COMMISSION'S ADVISORY
COMMITTEE ON NURSING HOME REFORM

Chairman

LEO McCARTHY, LIEUTENANT GOVERNOR

Highlights of Major Recommendations

From the Report

"THE BUREAUCRACY OF CARE"

December 1983

31-696 O—84——3

NURSING HOME RECOMMENDATIONS

The following are some of the major recommendations of the report "The Bureaucracy of Care." Lieutenant Governor Leo McCarthy chaired the Little Hoover Commission's Advisory Committee on Nursing Home Reform.

1. Expanded Consumer Information Services and Sources

- Create a statewide automated consumer information system to allow those in need of nursing home care to identify quality facilities -- building on the current Los Angeles County system.

- Increase consumer involvement through outreach and consultation by the State's Licensing and Certification Division with interested citizens, residents, ombudsmen, advocates, and consumer groups throughout the State.

- Require the Director of the Licensing and Certification Division to issue a press release to local newspapers when the Division takes action against an area facility, explaining the action and the conditions that brought it about.

2. Fines and Citations

- Increase maximum fines for "A" violations (which present imminent danger or death to a patient) from $5,000 to $10,000. Also increase fines for "B" violations (which have direct or immediate relationship to the health or security of a patient) from $50 - $250 to $100 - $1,000.

- Make retaliation or discrimination against any patient or employee who speaks out about conditions in a facility, a misdemeanor, subject to a fine of up to $10,000.

- Make falsification or omission of material in patient care records an "A" violation.

- Expand "B" violations to protect patients' rights, by redefining "B" violations as those that have a direct or immediate relationship to the health, safety, security, or welfare of a resident.

McCarthy
8/83

- Impose mandatory a jail sentence and a maximum fine of $50,000 on any licensed health professional who willfully abuses or neglects a patient.

3. Appeals of Citations and Fines

- Extend to complainants the statutory right to appeal the Division's determination -- a right already accorded the facilities involved.

- Give complainants, their representatives, and ombudsmen the right to participate in the citation review conferences.

- To reduce the time and expense involved in enforcing citations, reassign "B" violations from superior court to "a court of competent jurisdiction" -- which could be municipal, superior, or small claims court -- and allow the Licensing and Certification Division, instead of the Attorney General, to file small claims cases.

4. Sanctions Against Facilities

- Give the Division power to halt all admissions to a facility when it determines that the facility presents a threat to the health, safety, or welfare of residents.

- Withhold MediCal reimbursement to facilities that fail to pay their fines for 30 days or more.

5. MediCal Conversion

- Prohibit the transfer of patient because of conversion from self-pay status to MediCal.

- Require that facilities reveal their MediCal policies to the public in advance.

- Require (and provide funding for) facilities to hold MediCal residents' beds available for their return during brief periods of acute hospitalization (up to fifteen days).

- Prohibit discrimination on the basis of race, color, sex, creed, national origin, or source of payment with respect to admission or transfers by any MediCal participating facility that participates in the MediCal program.

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Mr. PEPPER. Mrs. Burton, do you have any questions?

Mrs. BURTON. As one who has a 91-year-old mother, and I hope that she never knows that I told her age, and a father who is 94 and just passed away a few months ago, I think I have lived with the problem of the aged and there are some in this room who know that I have lived with it.

What I want to ask you is: What does a nursing home have to go through in order to get qualified? And then how often are they monitored? Once every 6 months, every 3 months? Or is it just that someone finds a nursing home that is not working and not supplying the type of service they need to supply and are then investigated?

Mr. MCCARTHY. Yes.

Mrs. BURTON. The State nursing homes are licensed, aren't they? Would you answer that question for me?

Mr. MCCARTHY. Well, they have to obtain a license. The nursing home institutions have to go through routine financial responsibility requirements and have to demonstrate that they have some capability within the health professional staff that they hire to perform the job.

So that part's all right. The qualification procedures might be strengthened, but I think that's not the main target.

One of the main targets goes to the second issue that you raised. And that's the effectiveness of the inspection process. There's a Federal inspection process and a State inspection process. I really do think we could do a much better job in coordinating those two inspection processes, because the better nursing homes have sometimes complained that they often go through repetitive kinds of inspections and that sounds to me like a legitimate complaint.

But the spirit of the inspection process is what we have to worry about.

Nursing homes almost always know when an inspection is going to be made so that they can take pains to clean up what problems may exist.

One of the recommendations that we are making is to change the timing and the nature of the inspection process. It ought to be made at any time including at nighttime when it's not expected, or on the weekends, if you will.

And it does not need to be an inspection visit which looks at every single practice or item on the premises. The inspection could be segmented. You might want to look at diet at one time and other aspects of the nursing home on other occasions.

We've got to figure out how to do this efficiently and I think we can.

We had on the advisory committee expert people representing the nursing profession. We had industry people sitting on the committee and I think there was a lot of positive comment that we could change the inspection program so that it would not be so predictable and so that it would leave more lasting impressions on those nursing homes that will clean up for the visit and then lapse right back into their practices.

Mrs. BURTON. Are their licenses revoked when, let's say, you inspect a nursing home two or three times and you find that they're lacking in services?

Mr. McCarthy. The revocation of a license is not a satisfactory remedy. It takes forever to carry that through the procedures—the administrative procedures and court procedures.

So that nursing home can go on for several years and if it does lose—if it's at the point of revocation—the present owner will sell the nursing home to a new owner and the new owner will then promise to clean up the act of that nursing home.

The laws that I authored 10 years ago were to institute a citation system. We classified the more serious violations as class A and the fines could range up to $5,000 per violation.

Then class B violations would be something in the $50 to the $500 range.

We've also found that the institution of those fines has not been done in a satisfactory way by the State agency charged with that responsibility. Some commonsense needs to be applied.

If you're dealing with a nursing home that has a pretty good record overall and you go in and you find 10 class B violations, if you know that these are things that even good administrative oversight may miss and they really do have a record of cleaning up and then not lapsing back into violations after the inspection team leaves, you can use your discretion.

But there are many other instances in which the fines to be imposed are wiped out on more casual or less substantive grounds.

We're going to try and correct that and frankly one of the recommendations is to increase the level of fines from $5,000 to $10,000 for the class A violations and to boost them up subsequently.

We're also trying to provide other remedies to the State agency. Suspend medical payments. Do a number of in-between kinds of things well short of total revocation or suspension of a license which is really of no practical help to the elderly residents.

Mrs. Burton. Thank you very much.

Mr. Pepper. Mrs. Boxer, do you have any questions?

Mrs. Boxer. Yes; thank you, Mr. Chairman.

I want to ask you, Lieutenant Governor, if you feel that the recommendations of the Little Hoover Commission are really an all-encompassing type of recommendation.

Does it look at all the problems? And do you feel confident that if they were to be put to the test that we in this State would have taken a giant step forward in this area?

Mr. McCarthy. I think that we will take a giant step forward if all of these recommendations are adopted. But I want to add hastily that no law by itself is going to protect elderly people in so vulnerable a position in the kind of institutional care that we're discussing here unless the attitude on the part of elected and career governmental offices are such that the laws are going to be enforced with the view to the importance of the dignity and the individuality of elderly people in those homes.

And this attitudinal chasm still exists.

Mrs. Boxer. Will you make those recommendations part of the record of this committee, because I think it's very important.

Mr. McCarthy. I'd be happy to.

Mrs. Boxer. Have you discussed with the Governor his attitude toward the recommendations of the Little Hoover Commission? What was his attitude——

Mr. McCARTHY. I have not discussed them personally with the Governor yet. However, we did send the recommendations for analysis to the specific State agency charged with the responsibility, the Department of Health Services, for a review.

I'm very satisfied that the director of that particular department gave a fair and objective analysis of what it is.

Of course, that's what we need, because the recommendations will cost about $4 million to implement, but the biggest problem, frankly, is the industry and part of this industry is very cocky about its power in the legislature.

The industry thinks it's going to come in and thwart, with relative ease, in the committee process some of the tougher recommendations that we are proposing.

So, I'm going to need the Governor's help, but I'm very satisfied with the first step, and I'm going to seek the opportunity to talk to the Governor.

In fairness, he has not had the time to personally review the recommendations yet.

Mrs. BOXER. I just want to thank you very much for coming before us and also for your candor and openness regarding sometimes the very unfortunate influence of special interests in this legislation and I think that with public servants like you who don't hesitate to put it right there, I think we do have a fighting chance and I'm glad that you're here.

Thank you.

Mr. McCARTHY. Thank you.

Mr. PEPPER. Senator Mello, do you have any questions for Mr. McCarthy?

Mr. MELLO. Thank you, no.

Mr. PEPPER. Mrs. Moorhead, would you have any questions?

Ms. MOORHEAD. No.

Mr. PEPPER. Ms. Ream, would you have any questions?

Ms. REAM. No.

Mr. PEPPER. Governor, we thank you very much for your fine appearance here today.

Mr. McCARTHY. Thank you.

Mr. PEPPER. We now have a panel who will come to the table if they will, please.

First we have Hon. Hadley Hall who is the executive director of the San Francisco Home Health Services. Mr. Hall.

And then we have some Alzheimer's patients and care givers, Mrs. Elayne Brill, wife of a deceased Alzheimer's patient, accompanied by Mrs. Jeanne Kelly, Alzheimer's patient, and Mr. Arthur Kelly, her husband, a care giver.

We have also Mrs. Eva Olson of San Francisco, who is an Alzheimer's patient, accompanied by her granddaughter, Mrs. Margot Salvini.

We also have a pediatric home care recipient, accompanied by Mr. John Escheverria, past president of the Coalicion de Padres de la Bahia—Coalition of Parents of the Bay—San Francisco.

Pele Robinson, pediatric home care recipient, accompanied by Mrs. Delores Robinson, mother and caregiver.

We are very grateful for all of you for coming here this morning and giving your testimony on this pitiful matter.

First I'll start with Mr. Hall.

PANEL ONE, CONSISTING OF HADLEY DALE HALL, EXECUTIVE DIRECTOR, SAN FRANCISCO HOME HEALTH SERVICES, SAN FRANCISCO, CALIF.; ELAYNE BRILL, FAMILY SUPPORT GROUPS, SAN FRANCISCO BAY AREA; JEANNE KELLY, ALZHEIMER'S PATIENT, AND HER HUSBAND, ARTHUR KELLY, CAREGIVER, SAN FRANCISCO, CALIF.; DELORES ROBINSON, MOTHER AND CAREGIVER, SAN FRANCISCO, CALIF.; JOHN ECHEVERRIA, PAST PRESIDENT OF THE COALITION OF PARENTS OF THE BAY, SAN FRANCISCO; MICHAEL MEZA, PRESIDENT, COALICION DE PADRES DE LA BAHIA, SAN FRANCISCO, CALIF.

STATEMENT OF HADLEY DALE HALL

Mr. HALL. Thank you, Mr. Chairman.

My name is Hadley Dale Hall. I am executive director of the Visiting Nurse Association of San Francisco, Inc., San Francisco Home Health Service, and Hospice of San Francisco. I have been employed in home care in San Francisco for nearly 20 years.

Helping people with home care needs is not always easy. Problems are compounded when people are poor and need government help. In our agencies, a person can be eligible for medicare, medicaid, veterans' benefits, Older American Act funds, hospice care and many other government funded services. Each program responds to a need but none of these programs looks at the whole person. The result is fragmented services, costly bureaucracies, waste, and abuse of recipients as well as workers trying to care for the people in need.

Title XX is a Federal, State and local program. It has been the subject of repeated exposes in newspapers, television, and congressional hearings. Repeated promises are made to change things in this Government program, but the problems get worse. In California, this single Government program affects over 100,000 recipients and 80,000 workers, costing the taxpayers $500 million a year.

California's implementation of title XX, the inhome supportive services program, is a scandal whereby well paid public employees exploit workers and deny them their employee rights. The predictable result is abuse of the sick, the elderly and the poor. Before I describe the lastest abuses, may I respectfully request that an outcome of this hearing be a full and comprehensive investigation into the title XX program in California and its 58 counties and the title XX relationship to the other Government programs like medicare, medicaid, veterans' benefits, Hospice care and the Older American Act.

A report of this investigation should lead to new Federal legislation which will address the recognized problems of fragmentation and bureaucratic waste and abuse.

The competitive bidding and contracting processes for inhome supportive services have been referred to as jokes and shams. Part of the reason for the derision of public employees involved in these processes, is that some companies bid on one basis but execute the contract in quite a different way—sometimes with the knowledge and blessing of well-paid public and union officials.

For example:

The bid specifications may require a specific number of supervisors or an amount for vacation time. There are no known audits to determine the degree of relationship between a bid and actual performance. When material differences between a bid and performance are exposed, there seem to be no penalites or sanctions against the bidder, a contractor or the union and public officials charged with specific responsibilities.

The very concept of lowest bidder must be challenged as used in this program because the lowest hourly bidder is going to be the most expensive in total cost—in more ways than one: costly for the consumers, taxpayers, and workers as well as destructive of the basic belief held by all Americans that fairness and justice are available through our government and unions and their employees.

Lowest cost does not equal lowest hourly or unit price. To determine lowest cost, one must know the unit price plus the number of units—or hours—utilized in a given period of time, a month, for example. In addition, the length of stay must be known—how many months on the service—and the rate of recidivism must be known, that is, does the person get better and stay off the service or are they repetitively back on the service?

Testimony being submitted details continuing scandals in this vital and valued program. The testimonies tell a tale of abuse and waste and ask for a proper congressional investigation to determine if there are crimes being committed and what legislative remedies the Congress should consider.

Remedy Health Services has been a successful bidder on several in-home supportive service contracts in California countries at extremely low hourly rates. This has lead to speculation that in order for the company to make a profit, the company must take short cuts in the program and shortchange the government and the company's workers in terms of wages and fringe benefits through questionable cost cutting methods. Evidence is accumulating that these cost cutting methods are not speculation but are being used by Remedy. For example:

A. THE GOVERNMENT IS SHORTCHANGED

The union and Remedy agreed on August 16, 1983, after Remedy received the San Francisco inhome supportive services contract that each employee's regular wage rate would be reduced to 50 cents per hour and paid to the employee as a clothing maintenance allowance. It appears that this method of cost saving is a willful avoidance of Federal, State and county payroll taxes and legally required insurances. It is my understanding that a letter to this effect has been transmitted by the San Francisco Department of Social Services to the city and county of San Francisco attorney who has forwarded the letter to the Internal Revenue Service.

Although this questionable practice may leave a few dollars extra in the hands of the workers, it violates the law and the employer, under such a provision, would save $250,000 in unpaid employer required taxes and insurance premiums for things like social security and workers compensation, among others.

B. THE PROGRAM IS SHORTCHANGED

In San Francisco, there have been three trained and experienced supervisors terminated since mid-August, 1983. One of these employees was a nurse. Another had a professional social work background, and the third was fluent in Chinese. These individuals were replaced by personnel from the company's San Mateo County Office, I am told.

The contract in San Mateo calls for 10 field supervisors. Indications are that this contractual program need is not being met in San Mateo County because supervisors have been transferred to San Francisco. If I were an auditor, I would want to be assured that there were no double billing or costings as was found in the *Souza* case of several years ago.

THE WORKERS ARE SHORTCHANGED

The union contract between Remedy and the hospital and Institutional Workers Union, Local 250, requires that only 10 percent of the work force be employed as casual. The reason for this stipulation is to remove incentives from the employer to hire a large number of relatively short-term employees at the expense of the regular homemakers, many of whom have acquired training and experience as well as seniority for purposes of earnings and patient care skills. Indications are that this contractual commitment is being systematically violated by Remedy and that instead of having about 40 casual workers, as required by the union contract, Remedy has many more than this.

The union signed a favored nations union agreement. This favored nations clause means that other signators to the union contract can take advantage of benefits granted to a different employer. In this situation it would mean that San Francisco Home Health Service would have to participate in a willful avoidance of Federal, State, and county payroll taxes and legally required insurances and violate the purposes of having a limit on the number of casual employees.

If I were an investigator, I would want to assure myself that the agreements between Remedy and the union were properly negotiated and fairly reached. Indications are that there were sweetheart arrangements made.

Since regular hours worked at clients' homes and hours spent in transit between clients are lumped together on Remedy employee payroll checks, there is a logical suspicion that transit hours could be billed as service hours. If this were the case, it would violate the terms of the county contract and the program requirements. It would also appear, if true, to violate the union contract.

Field supervisors have been admonished to maximize the number of hours that each client receives so that the total contract hours can be raised and thus reduce the fixed cost component of Remedy's budget. For example, historically in San Francisco, the number of hours served is less than 80 percent of the number of hours authorized due to clients being hospitalized, out of town, family visits, and other reasons. The result of this type of increase is to raise the cost of services per client per month due to overutili-

zation of services without providing compensating benefits to the client or the taxpayer.

One should note that when workers are shortchanged, so is the program.

In the case cited previously, where Remedy is deducting 50 cents per hour from the employee's regular wages, the employee is being exploited. The employees are underpaying social security and Federal and State withholding taxes through no fault of their own. When the various taxing agencies require a full payment for back taxes, the workers will be required to pay on these earnings. I have previously submitted to the committee staff copies of court decisions on these matters.

The union contract calls for the employee and the employer to each contribute 5 cents per hour to an employees' pension fund. The money has been withheld by Remedy, we understand, but no accounting has been given to any of the employees. The question becomes, since the union contract requires that we follow the ERISA requirements for pension funds: what is happening to these monies?

I understand that Remedy has not explained to its workers how the workers' vacation time is being accrued. In the past, we have known of hundreds of homemakers who have not been paid their vacation by the employer and where the State of California appropriated additional funds to cover this expense following the bankruptcy of a major company.

The union contract requires that employees receive Kaiser Health Plan B medical coverage or its equivalent. It is my understanding that Remedy workers are receiving plan L, which is not equivalent. It costs the employees more, and the employer less.

The employees have requested that all hours accrued for regular wages, such as travel, sick leave, vacation, and training, among others, be listed on the paychecks so that they will know how these benefits are accumulated.

Recently, a union member complained to a shop steward of local 250 that Remedy was not paying appropriate travel time. The shop steward was able to get the local Remedy manager to admit that Remedy employees had been instructed to shortchange employees some 200 hours of travel time each month, I am told.

It would appear, from several employee complaints, that senior workers' hours are being reduced and that these hours are being replaced by casual employees. This, of course, reduces the quality of the program, saves the employer money because they are paying less in terms of wages and fringe benefits, and the practice thoroughly demoralizes the existing work force.

In short, Mr. Chairman, it would appear that the problems of title XX continue. The problems have been well-documented and reforms have been promised repeatedly. Yet, as before, I request your help in obtaining the facts about this company and ask for changes in the current system which seems to encourage dishonest employers such as Gottreiner and Sousa.

I will be glad to work with your staff and others to offer suggested solutions and to get to the root of these problems.

The panel that is here today are recipients and people who have been involved with Alzheimer's disease: Mrs. Brill; a patient, Mrs.

Kelly; her husband, Mr. Kelly; and a mother of a handicapped child who is in need of services, Delores Robinson. In addition, representatives of the Coalition of Families of the Bay will testify. This is a group of Spanish-speaking parents of developmentally disabled children who have great difficulty finding the services they need. Rather than me, taking up your time, sir, trying to tell their story, I think it better for them to speak.

Perhaps Mrs. Brill could start.

Mr. PEPPER. Thank you very much.

Mrs. Brill, we welcome you and thank you for your statement.

STATEMENT OF ELAYNE BRILL

Ms. BRILL. Mr. Chairman and members of the committee, my name is Elayne Brill and I am the founder of the family support groups in the San Francisco Bay area.

There are six: Menlo Park, San Jose, Hayward, Berkeley, Marin, with San Francisco having started November 7.

They are all affiliated with the Alzheimer's Disease & Related Disorders Association, ADRDA, located in Chicago.

Thank you for allowing me to appear before you and for the opportunity to represent hundreds of families in the San Francisco Bay area who have loved ones with Alzheimer's disease.

I found out that my husband had Alzheimer's disease 5 months before he died. Not that we hadn't been seeking help, but at that time, mid to late 1970's, the doctors consulted never mentioned the disease and probably did not know anything about it themselves.

Finally, in 1980, my husband underwent a complete diagnostic examination. I was told that he had a dementia probably caused by alcohol and would soon need 24-hour care.

It was only when we moved to San Diego in January 1981 that I was able to get the proper diagnosis, which was confirmed upon autopsy as my husband died 5 months later.

He also had cancer for which I was thankful, a comment which an Alzheimer family member easily understands.

During the time that George was dying in San Diego, I was fortunate enough to be part of an Alzheimer's disease family-support group. Their comfort and caring kept me from having a nervous breakdown.

It was there that I first became aware of the financial burden that Alzheimer families experience.

My husband died before I was in that position. After George died, I decided to move to the San Francisco Bay area and realized the need for family-support groups there.

In January 1982, I started organizing the groups. Because of my close association with the families, I became aware of the lack of financial help for these people.

I am appalled that so many of these families had lived comfortable lives, but now are reduced to poverty. Government help is not available for Alzheimer's disease families. The world of health care does not recognize Alzheimer's disease as a physical disease. Therefore, provisions do not exist in any insurance plans, Government or private, for the care of the patient.

The caregiver is forced to keep the patient home as placement in a facility costs approximately $20,000 to $25,000 annually.

With this institutionalization lasting up to 10 years or more, even if the family has saved this kind of money, there is nothing left for the survivors; therefore, the desperation.

By delaying institutionalization for the patient because of lack of funds, the caregivers deteriorate mentally and physically. They fall prey to stroke, ulcers, cancer, and nervous breakdowns.

These families end up with more than one Alzheimer's victim.

As the disease progresses, the patient needs 24-hour care, becomes incontinent, and then bedridden, not recognizing family or environment.

These conditions are impossible for the caregiver on a 24-hour basis or actually we say a 36-hour day as per the book.

An example of this is attached in a letter from a caregiver from the East Bay which will be submitted with this.

I receive hundreds of phone calls from caregivers asking questions like the following:

What can I do to keep from going crazy? I can't leave my house because I have no one with whom to leave my husband or wife.

How can I get just one night's sleep? My patient is up all night rampaging around the house.

Where can I find a day-care center that I can afford?

I can't afford a nursing home and yet the time has come. What can I do?

If I put my patient in a facility, there will be no money left. How will I live?

Our family is torn apart because our children do not understand this disease. What can we do?

I must work to survive. Who can take care of my patient who now needs 24-hour care?

Where can we go for help? Our hands are tied.

If funds were available for respite care in the form of homemakers, transportation, nutritional food, psychological counseling, babysitting services, and other in-home services, it would be possible for the caregivers to survive this ordeal and cope with the daily care of the Alzheimer's patient.

This would help to alleviate another major problem, patient abuse. The lack of respite resulting in utter frustration on the part of the caregiver is responsible for the tragic abuse, both emotionally and physically, of the patient, this issue being very common.

At this time a respite-care program is not available for these families. When are we going to help these families who have no other way of preventing this disease?

Alzheimer's disease is unlike other diseases such as heart disease, cancer, and strokes which can be self-inflicted by persons who are overweight, who smoke, who drink alcohol excessively, who overindulge in salt and sugar and who do not participate in any form of exercise.

Our Government helps these problems and yet penalizes the Alzheimer disease patients and families.

If there was a choice, Alzheimer's families would prefer cancer, heart disease, or anything other than Alzheimer's disease for their loved ones.

Our people are forced into divorce after many years of marriage. This is being done in order to survive financially. Having to resort to this is just one more trauma for families.

Please note another attached letter from the president of the San Jose group who is undergoing a divorce.

What can be done to extend medicare coverage to help our Alzheimer's families? At least we should have a consistent Veterans' Administration policy, with such policy set that each VA hospital throughout the country will take care of the Alzheimer's patients instead of the way it exists now with only some of them living up to the responsibility.

Our disability program is inconsistent. Qualifications and guidelines are not well defined and are incomplete. Therefore, mental impairment is ineligible, even though Alzheimer's disease is a disease and not a mental illness.

The legislation to provide homemaker-home-health aid, in home respite, and day care is a step in the right direction.

It is hoped that this committee would find it appropriate to call upon my organization to help design and review the most necessary services applicable to this aspect of the care and hopefully will make provisions for people who are in their 40's, and 50's, and even younger who have this disease and could possibly live up to 50 years longer.

This is not only a disease of the elderly, even though those afflicted generally are past 60.

The research community for Alzheimer's disease has made it clear that the answer to the disease and/or possible intervention and treatment are not imminent and can be up to 10 years away. By that time, more than 5 million people in the United States will have Alzheimer's disease and presently we have no way to care for them.

How are we going to help these families survive?

I could not bear the indignity of the disease for myself nor could I submit my children to such a tragedy. Therefore, if I were told I had Alzheimer's disease, I would carefully confirm the diagnosis and put my affairs in order.

Thank you for allowing me to be heard as a spokesperson for the hundreds of people who are members of my group and the thousands more in the Bay Area with Alzheimer's disease.

Mr. PEPPER. Thank you very much, Mrs. Brill, for your excellent statement.

Are there any questions from anyone on the dais?

Mrs. BURTON. Would you tell us some of the symptoms of Alzheimer's disease?

Ms. BRILL. The first symptom is simple memory loss, complicated by confusion; confusion as when a patient has had lunch a half an hour before and requests lunch, or the confusion of losing things constantly.

We all lose things. We mislay our keys, but when one does it six or eight times a day, and there's also usually a personality change, somebody who has always been rather placid could become very volatile, and hostile, or vice versa.

Those are the beginning symptoms.

Mrs. BURTON. Thank you.

Mr. PEPPER. May I ask the members to reserve their questions until we've completed the panel.

Next, we'll have Mrs. Kelly.

Mrs. Kelly, we welcome your statement or the statement of your husband.

Please give the microphone to Mrs. Kelly.

STATEMENT OF JEANNE KELLY

Ms. KELLY. I'm Jeanne Kelly and I have Alzheimer's disease, and I have had this, that I know of, approximately 4 years. I had never heard of this disease, but when I first noticed something was wrong was when I attempted to write a check and when I wrote my name Jeanne, J-e-a-n-n-e, I wrote it J-e-a-n-n-e-e-e-e, and later on I attemped to drive my automobile and I couldn't find my way home, four blocks.

And I went to my family doctor, was referred to a neurologist and he said I had Alzheimer's disease.

Now, at the present time, I am not in a——

[Pause.]

I know what I want to say but those words don't come out.

Most of the time I'm just fine, do things properly, though I have trouble getting into my clothes sometimes.

Every morning when I get up and get dressed and call my husband: "It's bra time," he's got to put my bra on for me. We make a game of it.

I don't think that I am progressing—I think that if—that I'm not as—yes, I'm more or less stable but now I'm a little bit nervous, because I'm speaking to all of you lovely people.

I have accepted the fact that I have this disease. I try to make the best of it, and I want to continue doing things that I want to do, if I can do them. If I can't do them, my husband does them for me.

I'm trying to live a normal life as much as possible, but also in the back of your head you say, "I know as this gets worse, and worse, and worse, I am going to need help and ongoing help and it will go on and on until the time——"

But I personally am trying to live as normal a life as I can at the present time.

Mr. PEPPER. Thank you very much, Mrs. Kelly.

Mr. Kelly, would you like to add anything?

STATEMENT OF ARTHUR KELLY

Mr. KELLY. I know that Jeanne would like to thank Mrs. Boxer for helping in a former matter but, by the same token, in a year's time you can gradually see the change that is being made.

You have to go back 1 year to understand what's happening now. Living with a person it's hard to see the changes, because you are together every day. But thinking back and weighing things from 1 year ago and today, you can see the changes being made.

She has put her affairs in order, and if anything happens to me, she will go with her daughters, instead of the nursing care, hospice care, and this is what Mr. McCarthy and Mr. Mello was talking

about, which would fit in perfectly with that, because a convalescent home or things like that is not for her.

Cheaper—as Leo McCarthy said.

This is one of the problems, and she knows that it's going to get worse. I do, too.

And there's a book out on it called "The Thirty-six Hour Day," which you have to read and see, as myself, the caretaker, knows what to expect and can cope with that.

Thank you.

Mr. PEPPER. Thank you both for being here. You present a tragic case.

Thank you very much.

Ms. KELLY. Thank him a thousand times. I love him dearly.

Mr. PEPPER. Thank you, Mrs. Kelly.

Our next witness will be Mrs. Robinson.

Mrs. Robinson, we welcome your statement.

STATEMENT OF DELORES ROBINSON

Ms. ROBINSON. Mr. Chairman, I am Delores Robinson and I live at 1526 Waller Street in San Francisco. I am 32 years old and have three children: Doreen who is 14 years old, Mitchell who is 12 years old, and Pele who is 5.

Pele was born with a handicap called spina bifida. The doctors describe this as a defective closure of the bony encasement of the spinal cord, but spina bifida is most frequently called open spine.

It is one thing to know that you have a child that is born with a handicap, but it is quite another realization to know that modern-day medicine can't cure my son.

Frequently Pele's mind is OK. In fact, it's pretty good. The school tells me that he's been doing very well and that he's even advanced in some areas.

Trying to take care of Pele by myself is extremely hard. Even though my older two children and Pele's father help out sometimes, his care primarily falls on me.

My whole life feels totally consumed with taking care of my disabled son. My family, friends, and neighbors feel sad about Pele's condition, but they don't really fully understand what it's all about. They say they would like to help, but the braces, diapers, and medications all scare them away from helping to take care of him or really support me in practical help with my son.

It's really hard trying to raise a child who is severely disabled, because it takes up most of your time. When he's not in school, I take Pele with me almost everywhere I go. People ask me hundreds of questions about his condition all the time. They never stop.

During Pele's first 3 years, I received help from the Department of Social Services and the Golden State Regional Center. Each of these agencies sent me a homemaker. The DSS worker came several hours a day 2 days a week.

The regional center sent a homemaker from a commercial company on weekends for a few hours.

I receive a total of 11 hours a week from these homemakers. They help take care of Pele and give me some time to myself. They

are a big help just playing with him and watching over him. It gives me the break that I needed.

This homemaker was a wonderful lady. They cared and weren't afraid of my son like some of my friends.

The ladies even gave me practical help. I guess they were trained to help me and my son.

Pele started right to school when he turned 3 and these two agencies quickly stopped providing services to him. They both said that with Pele in school we were no longer eligible for their services.

Pele will always need regular physical therapy to continue to strengthen his legs so that he can at least hobble. They give him physical therapy at school, but they say I should repeat the exercise at home with him, even though some of the exercises require two people.

I go to his school frequently to learn what exercises I should do with Pele, but it's hard to repeat them by myself at home.

What I really need is someone who knows about Pele's condition, who isn't afraid to see him hobble and fall, can lift him up, help him with his bath, assist him in personal care, and help teach him what he can do for himself.

Pele also needs a physical therapist to come to our house and work with me on the exercises. If I had these services at home, Pele's hygiene and physical fitness would be much better.

This in turn would help his self-image and he would play better with other children.

Not to give him this fighting chance would make him even more dependent than he is now.

Thank you for this opportunity to tell this story.

I hope this community will help handicapped children to stay in their homes with their physical therapists, respite care and other needed services.

Thank you.

Mr. PEPPER. Thank you very much, Mrs. Robinson, for your excellent statement, also.

Our next witness is Mr. John Echeverria.

We'll be glad to hear from you, Mr. Echeverria.

STATEMENT OF JOHN ECHEVERRIA

Mr. ECHEVERRIA. Mr. Chairman, for the moment I am going to pass to Mike Meza. He's the actual president of the group, this group of parents of handicapped children.

So I'm going to let him read the testimony.

Mr. PEPPER. You're the past president of the Coalition of the Parents of the Bay.

Mr. ECHEVERRIA. I was president. He's the actual president.

Mr. PEPPER. Now, Mr. Mike Meza is the current president of the Coalition of Parents of the Bay.

Mr. ECHEVERRIA. Yes, sir.

Mr. PEPPER. Mr. Meza, we are pleased to hear from you.

STATEMENT OF MICHAEL MEZA

Mr. MEZA. I am Mike Meza, president of Coalicion de Padres de la Bahia, an Hispanic family group here in San Francisco.

I represent families with children who have autism, Down's syndrome, mental retardation, cerebral palsy, and deafness.

Many of our family members are noticing what the budget cuts have been doing. They are lacking some services and being reduced in their respite care, which we all know they need mostly.

My sister, Mary, was born with Down's syndrome, and recently I was made guardian to her upon the death of my mother. I'm aware as well that Mary was in a State home at one time, and then returned home. I recall that a few years ago many of the State hospital patients returned to the community, but somehow or another their fundings did not really follow them or keep up with them.

We have family members who, because their children are deaf, find that there are problems in actually getting services, because our families primarily have maintained their home languages which in our case is primarily Spanish.

We find that there is some difficulty in communicating or finding someone who can communicate with us in Spanish to convey whatever is needed.

I am also a member of a State council of Hispanics, and this last August, I believe, we had a educational festival at USC. This is the second year that USC has sponsored us and the sixth year that this group has gotten together to help to educate the Hispanic families in Spanish and make any laws, mandates available to them, familiarizing them with services that are available to them, either from the State community or Federal.

Some things that many of us as the elderly do need is transportation, medication, and long-term services. True, our children, being born with these difficulties, had this need from that time and I feel that I may even be in the wrong place, because this is a committee for aging and these children do require these services from the start.

I've digressed from my prepared statement.

We find also that the Golden Gate Regional Center, which is our funding agency here within the San Mateo, San Francisco, and Marin County is doing some outreach service for us; yes, but they do not really assist us with all the needs than to, you might say, at the last moment just before we go to Los Angeles for this educational festival, they provided us with names.

This year they did not provide us with the fundings or any real help.

We as a family group aligned ourselves with the [illegible] de Ninos from Oakland and did fund raising, and we are both helping each other in any way that we can.

Respite care is one area which has been cut back in the recent budget cuts, and we're being informed that it will be cut back even further.

Naturally, there are times when family members, individuals who are responsible for their care, children, would like, say, privacy timeout, to do whatever they would like to do to enjoy their life as well, instead of being so tied down to a total responsibility.

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True enough, many of our children, sons and daughters, that is, who do not have these needs are not familiar or know how to handle their own children, brothers and sisters. There are individuals who, through the process of respite, can be taught, are taught, are familiar with the needs of most handicapped individuals.

I should like to thank the chairman, the committee for my time.

Mr. PEPPER. Thank you very much, Mr. Meza. Are there any questions from the dais?

[The prepared statement of Mr. Meza follows:]

PREPARED STATEMENT OF MICHAEL MEZA, PRESIDENT, COALICION DE PADRES DE LA BAHIA

My name is Mike Meza, I live at 55 Leland Street, San Francisco, California, 94134. I am 40 years old. I operate a forklift for Heublein, Inc. I am the legal guardian of my sister, Mary, who is 43 and suffers from Downs Syndrome.

I am also the President of the Coalicion de Padres de la Bahia located at 464 30th Street, San Francisco, California, 94131. We are a group of 200 Hispanic parents of children with development disabilities requiring long-term care.

Our children suffer from autism, Downs Syndrome, Mental Retardation, Cerebral Palsy, Deafness, and other serious disabilities which require long-term care. As Hispanic families we face many day-to-day problems in getting services which will stimulate and educate our children as well as maintain the integrity of our families.

I am pleased to have the opportunity to explain what the problems are as we see them. I hope that the location of these hearings in the "Ceremonial Courtroom" do not represent the government's intention to consider our problems in a ritualistic fashion.

Here are some examples of the problems we experience on a daily basis.

Mrs. Guitierrez's son, Rene, has cerebral palsy. Even though Rene is very bright, he is not getting the attention at school that he needs. This is so despite the existence of the mandated Individual Education Plan (IEP). Though the plan takes into account most of Rene's needs, the actual services that he receives at school are inadequate.

Mrs. Frias' son, Alexander, is in the sixth grade. He is deaf. He seems to benefit from speech therapy but only gets it one half hour per day. It is insulting that the speech therapy is in English rather than Spanish, the language spoken at home.

Mrs. Burgos has a heart condition. Rosemary, her 25 year old daughter, has a very serious heart defect. She attends a special school on Valencia Street. Mrs. Burgos worries that even a slight accident could have a terrible affect on her fragile daughter. Recently, Mrs. Burgos discovered that her daughter had fallen and hurt herself. But the school staff had neglected to inform her. When she went to the school to protest, the staff told her that she was overprotective. Mrs. Burgos complains that communication is very poor between the Anglo school staff and Hispanic parents.

Mrs. Malcado's daughter is 13. Claudia is mentally retarded. Mrs. Malcado complains that the Presidio school where her daughter attends does not provide adequate supervision. Twice her daughter has come home with bruises. Yet no note or call from the staff followed. When Mrs. Malcado went to the school to talk with the staff, one teacher said that Claudia needed to be physically restrained—tied down in a chair.

Another parent in our group has a son, age 26, who has no memory. He is unable to travel alone. He attends the Margaret O'Connell School which is located at the corner of Fell and Divisadero. This is a very busy intersection. One day, one parent went to the school and discovered the son's teacher reading a book while the children went unsupervised. Why is it this particular boy is sent to a school on such a busy corner? Why are there not enough aides to supervise our children when they are away from home.

We have faced these problems as an organization since 1978 when we realized that our interests as Hispanic families were not being represented through the existing health care and social service structure. One aim of the COALICION is to gain access to services for our children which will enable them to be as self-sufficient as their disabilities may permit. Since we are close knit families, our organization also seeks to gain access to services which are sensitive to our cultural patterns.

Recently, after years of effort, we succeeded in having one of our members appointed to the Board of Directors of the Golden Gate Regional Center. This is the first time in our memory that a Hispanic person has held such a position.

Our main concerns is that long-term care for our children is inadequate, fragmented and inflexible, and insensitive to our family oriented culture.

We estimate that there are 2000 seriously disabled children living in San Francisco who are eligible for long-term care services. Yet, only 250 Hispanic children have actually received services from 1965 to 1979. As more families immigrate to San Francisco from Central America and other parts of the world, the demand for culturally diversified services can only grow.

Outreach is needed. Few Hispanic parents know that services are available and that their children may qualify. And when services are provided, our parents must be educated that avenues exist to protect their interests as parents. They must be told, for example, that Individual Educational Plans may be appealed and that they must be designed and implemented within a reasonable period of time.

Respite care pays for babysitters. But we do not want simple babysitters. We don't farm out our children to the lowest bidder. We want trained people. Besides having skill in dealing with different disabilities, these aides should be trained in the ways of family oriented culture. These qualities should also be reflected in the way these aides are supervised and managed.

Ninety percent (90%) of the disabled children in our group need speech therapy. One half hour per day is not enough. There are no Spanish-speaking speech therapists working with our children. Can there be any excuse for such omission, such injustice?

Our older children need the most help. Our teenagers are not supervised in the high schools. There are not enough aides to care for their personal needs at school. Some parents send their grown and continent children to school in diapers simply because there are no aides to assist with toileting.

We need translators to improve communication between parent and schools. We need special transportation to get our children to special schools. Mainstreaming is not working. The Individual Education Plan is a plan in name only.

There are few provisions for our children once they have passed school age. Often we must find places for them in institutions at great expense to ourselves and to other taxpayers. The toll on our family unity is very high.

Our children change as they grow older. Their needs change. As the months and years go by we can see the effects of inadequate and inflexible long-term care services. The burden is borne by our children who do not receive the opportunity to reach their potential. The burden is felt by our families who cannot help with speech problems because the professional therapy is conducted in English. And the burden is carried by society for the institutional care which become more likely as our children age.

Mrs. BOXER. I have one.

Mr. PEPPER. Mrs. Boxer.

Mrs. BOXER. I want to thank the panel for their very good testimony, given from the heart.

Sometimes I wish that our President, who makes statements stating there is no poverty and no problems and no hunger, would sit in on some of these hearings himself.

I would like to address one question, if I might, to the Kellys. You are blessed with something that a lot of people don't have, and that's an extremely loving relationship, and as I sat and listened to you, I felt that very strongly come across.

My question is, Mr. Kelly: You're a very strong and healthy man and what if something were to happen to you, an accident, let's say, an auto accident, and you couldn't provide the type of care you're providing? What would your options be? And take it a couple of steps.

You may have family who would assist, but if that wasn't available, what would your options today be that would help your wife in her current status?

Mr. KELLY. Well, we mentioned earlier her daughters have agreed to take care of her in a case of this kind.

Of course, they're working like everybody does. A husband and wife have to work today, but they will try and see that they have somebody in the house to care for her while they were working.

So that's what I meant when I said that she had arranged for all of her affairs to be in order in case something like what you just mentioned should happen.

This is why I think this hospice would be an excellent idea, because she will not go into a convalescent home or a nursing home.

Mrs. BOXER. You're a very fortunate family.

Could I ask, Mr. Chairman, if Ms. Brill could comment on her experience with patients that don't have loving families, what are they doing? Are they getting any home care, and how are they paying for it at this point?

Ms. BRILL. It is amazing that a single person is favored, because the single person immediately can go on what we call here medical and so that person is taken care of.

It usually is the married couple that ends up destitute, because in order for the patient to receive medical, the spouse has to be poverty stricken, and it creates the situation where we have to provide for two people and not one.

So therefore, the single person does—the single person is taken care of a little bit better.

Ms. MOORHEAD. May I make a comment?

Mr. PEPPER. Go ahead.

Ms. MOORHEAD. One comment and a followup on what Mrs. Brill just said that we heard in our testimony and that is what you say is absolutely true, except that it's very difficult for a nursing home that will accept an Alzheimer's patient, because the Alzheimer's patient tends to be a patient that walks a lot, wanders a lot and we have a policy that you have to have an open door in nursing homes. The only locked facilities that we allow in California are acute psychiatric facilities which are entirely inappropriate for the Alzheimer's patient.

That will be a licensing battle that I will be fighting in January to try to set up a licensing category so that we can have secured facilities for our Alzheimer's patients.

The comment that I really wanted to make also was that, Mrs. Brill, you commented that it took a while for your husband to get the correct diagnosis and the diagnosis was only made 5 months, I think you said, before he died.

That seems to be one of the bottom-line concerns, that we have to get better diagnosis. To that end, I introduced a bill last year in our California legislature to set up academic geriatric resource centers in our colleges and universities. The Governor vetoed my bill.

So the message that I have is that it's going to be a long and difficult fight and we have to fight it together.

I took all the money out of the bill and said that we should just leave the intent in there. We have to get professionals trained so that we can begin to build this system with early diagnosis and I couldn't get that.

I will come back with that bill next year and maybe with a little help from Washington, we can do it together.

Mr. PEPPER. Mrs. Ream?

Ms. REAM. I would just like to make a comment about one program in San Francisco.

Mt. Zion Hospital came to the Commission on Aging this last year and really began to educate us about this issue of the need for some kind of specific day care program for Alzheimer's disease patients. We thought this was a marvelous idea and the original intent had been to cofund the Mt. Zion program additional funding from medicare.

Their mental health care programs were cut back. We've had to start at a very small level, one day a week, but it's, I think, one of the encouraging activities that is going on in San Francisco.

I think the need is financial—but I think that it is also programmatic. We need to begin to develop some sense of what the limits are at each stage on Alzheimer and how we can not only help that patient, but how we can also help the family.

The kind of coordinated effort at Mt. Zion is beginning to provide, on a very limited basis, some of the information on this, and I thank all of the panel for coming and sharing their experiences with us today.

Mr. PEPPER. Are there other questions?

Ms. BURTON. No.

Mr. PEPPER. I would just like to observe, from the statements made by all of you here, that if you have Alzheimer's disease, you're not covered by medicare.

The only coverage you get at the present time is under medicaid. You have to be impoverished practically to get anything from medicaid. That's down to the point of destitution almost, and I'm told that the institutions here, and I guess it's true over the country, don't like to take Alzheimer's patients if they're paid for by medicaid.

Is that your observation?

So we can see the problem that it imposes upon the people that we call ordinary people, people of ordinary means, if this terrible disease strikes them.

Mrs. Brill, was your husband in an institution at any time, and how much did it cost to care for him in his lifetime?

Ms. BRILL. I kept him home most of the time. The only time he had to be institutionalized is when he underwent—we underwent—two major surgeries with him because of his cancer.

So in between, before they reversed the colostomy, he had to be in the nursing home. That cost $60 a day. And after the colostomy was closed, I was advised not to bring him home, and that also ran $60 a day, but that was near the end of his life when I had no idea what was the matter with him.

It was finally then that I found out.

Mr. PEPPER. Well, you can see right here there are four people who are victims and their families—victims of this terrible disease which is now, as I said, the fourth largest killer in the United States.

You can see what a serious problem this presents to our society, to find some way to handle this horrible disease.

Well, we want to thank all of you today for coming here and giving us your excellent testimony.

Thank you very much.

We'll call another panel and then we'll take a 5-minute recess, please, and resume the hearing.

The next panel may come up to the table, if they will.

They are a panel of long-term care policy experts and service providers.

The Honorable Joe Barbaccia, doctor, professor and chairman of family and community medicine, University of California at San Francisco.

Dr. William Gee, On Lok Senior Health Services of San Francisco.

Mrs. Brahna Trager of San Geronimo, California.

And Dr. Carroll Estes, Aging Health Policy Center, University of California, San Francisco, who will be accompanied by Dr. Robert Newcomber and Mr. Albert Benjamin.

Are they all here, the ones I called?

The others will please all come up to the table.

We'll take a 5-minute recess and then we'll resume.

[A brief recess was taken]

Mr. PEPPER. On the record.

We will hear Dr. Silverman first.

Doctor, we appreciate your distinguished mayor asking you to come and speak here for her and for your area. We appreciate having you and we welcome your statement.

STATEMENT OF DR. MARVIN SILVERMAN, DIRECTOR OF HEALTH SERVICES FOR THE CITY AND COUNTY OF SAN FRANCISCO

Dr. SILVERMAN. Thank you very much, Congressman Pepper, Congresswoman Burton, Congresswoman Boxer, Senator Mello, Assemblywoman Moorhead, and Ms. Ream. It's a real pleasure for me to be here and represent the mayor and speak to you about long-term care.

In my remarks this morning, I would like to briefly provide you with an overview of the problems associated with the delivery of long-term care services. Then I will discuss some solutions which we've undertaken here in San Francisco and some solutions that I believe we need to consider as a matter of national policy.

The current delivery system is characterized both by access limitations and continually escalating costs to the taxpayer.

The term "limited access to services" refers to three separate but interrelated problems.

First, the systems bias toward institutional care which may cause it to be the only treatment option.

Second, the unavailability of some services.

Third, the difficulty of putting together a package of services for clients with needs across bureaucratic lines.

The exclusion of many community-based alternatives to institutionalization from the list of medicaid reimbursable services is a manifestation of the first problem of bias toward institutional care. We often think in terms of placement rather than searching for alternatives, and when we do initiate that search, we find that with few exceptions most third party reimbursement sources have not included these services in their insurance package.

Not surprisingly, the second problem, an insufficient supply of certain services, is usually found among community based services such as adult day health care. However, exceptions do exist and inadequacies among institution based services are observed. In San Francisco, for example, we have a shortage of nursing home beds. This has resulted in many public sector patients being placed in facilities as far as 40 to 50 miles from their families and friends which often prolongs their stay and causes unnecessary stress and hardship both for the individual and to the family.

The third problem, the difficulty in packaging an appropriate level and an intensity of services, is most critical.

The current long-term care delivery system is characterized by separate funding sources with distinct service and eligibility requirements.

Each pool of funds supports a different set of programs. Occasionally, eligibility in one program guarantees eligibility in another. Sometimes complementary service packages can be arranged. Most of the time, however, the services do not interrelate, unless someone, the client, the professional, or the family, makes a conscious attempt to use all of the system's resources to deliver as coordinated a package of services as is possible given the previously mentioned constraints on the delivery system.

It's easy to see how this system creates inefficiencies. It has developed by adding categorical programs in response to perceived needs, and it lacks coherence.

Since its source of funding is discreet, it lacks integration as it adapts to fewer financial resources. It cuts services whose absence may cause greater expense in the future. I would like to briefly address the cost question at this point.

An analysis of the rapid rise of taxpayer borne, long-term care costs, must consider multiple variables. Inappropriate use of costly institutional services is but one of the many causes of escalating costs.

First we must look at the increase in the total number of elderly. In California, the 65 plus population grew by 13 percent between 1970 and 1980.

Second, there's been an increase in the number of seniors needing a more intense level of services. These individuals are generally older and live alone.

This population, which is at risk because of its age, has grown dramatically nationwide. In our State, the 85 plus population has grown by 28.8 percent in the past 10 years.

Third, there have been profound shifts in family composition and an increase in the number of women entering the work force which have resulted in a greater reliance on a formal rather than an informal support system.

Fourth, inflation and health care price increases have contributed to cost escalation.

Fifth, the incentive structure governing the health care industry and the skewed relationship between supply and demand have had a spiraling effect on both the public and private costs.

The difficult task, of course, is to solve these problems. I believe some of the solutions emerge from the problem analysis I have just presented.

First, I would like to address the bias towards institutional care.

Third-party reimbursement must be available for the entire continuum of long-term care services. I concur with the suggestion that the Federal Government create a part C under medicare to underwrite the cost of long-term care services.

Looking at the private sector, the insurance industry has been very successful in designing and marketing policies which supplement the coverage provided by medicare. I believe these policies currently provide some of the needed insurance protection for seniors and will continue to do so even if we develop a medicare, part C.

However, as this committee well knows, elderly consumers also must be secure against the abuses of the industry.

Efforts to provide protection have been undertaken in many States and by the Federal Government. I believe these efforts should be continued and should be strengthened.

Second, I would like to address the unavailability of certain services. When adequate reimbursement and seed money to cover startup costs are obtainable, services will be accessible.

The availability of adult day health care in San Francisco is a case in point. California passed the Adult Day Health Care Act allowing medicaid reimbursement for Adult Day Health Services in 1977 and subsequently authorized startup grants to programs through SB50 and SB134 authored by Senator Mello.

San Francisco's private foundations with United Way's prodding underwrote an additional $900,000 in start-up costs and the Health Department committed some of its resources as well.

The result of this endeavor is a network of adult day health care in this city which is unparalleled anywhere else in the country.

This example of a public-private effort to provide reimbursement and seed money can and should be replicated.

Third, I would like to consider the packaging of services. In San Francisco, we have three ongoing long-term care demonstration projects and one which will begin this January.

Using medicare and medicaid waivers and employing a case management process, On Lok, the multipurpose senior service protram project opened and soon the department's elder care program have or will have delivered an appropriate mix of services to a portion of the frail, at-risk population in San Francisco in an efficient and cost-effective manner.

These experiences have taught us the importance of broadening the amount and scope of service provided the clients as well as the importance of case management to the health care process.

I would urge at a minimum that the 2176 waiver regulations be broadly interpreted to allow States to serve as many clients as possible so long as aggregate costs remain the same.

I would also like to see a real expansion in the number and type of coordinated systems available under 2176 or 1115 waivers as well as third party reimbursement for case management services outside of the waiver process.

Finally, I believe we need to consider the cost question in a rational manner. Costs have escalated in part because of the sociodemographic changes that I have mentioned which we cannot affect.

Costs have also escalated in part because of inflation, the problem with which we are all too familiar.

Long-term health care costs, however, have escalated like health care costs in general, because of the incentive structure governing the delivery system and the skewed relationship between supply and demand.

I believe many of the cost containment measures currently being applied to acute care institutions may be applicable to long-term care services. I would caution policymakers addressing the cost question to consider the commitment of this country backed by 20 years of national policy to its senior population. Certainly we must be judicious in expenditure of taxpayer dollars.

Expensive services must not be purchased if less expensive alternatives can provide the same result, but neither should we shift costs on those who are least able to bear the burden, our elderly.

Our solution to rising costs must come from the sound analysis of the underlying causality as well as a human approach to the problem.

I sincerely appreciate the opportunity to address you. It's been my pleasure and I hope that if you have any questions that I will be able to answer them.

Mr. PEPPER. Thank you very much, Dr. Silverman. We appreciate your being here and your excellent statement.

Are there any questions from the dais for Dr. Silverman?

[No response.]

Thank you very much, Doctor. Please give our appreciation to your distinguished mayor.

Now, we'll revert to our panel which is at the table.

First we'll hear from the Honorable Dr. Barbaccia, doctor professor, and chairman of Family and Community Medicine, University of California at San Francisco.

PANEL TWO, CONSISTING OF JOSEPH BARBACCIA, M.D., PROFESSOR AND CHAIRMAN OF FAMILY AND COMMUNITY MEDICINE, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO; WILLIAM GEE, D.D.S., ON LOK SENIOR HEALTH SERVICES, SAN FRANSCISCO; BRAHNA TRAGER, SAN GERONIMO, CALIF.; CARROLL ESTES, PH. D., DIRECTOR, AGING HEALTH POLICY CENTER, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

STATEMENT OF DR. JOSEPH BARBACCIA

Dr. BARBACCIA. Thank you.

Your Honor, Congressman Pepper, members of the panel, ladies and gentlemen, again my name is Joseph Ciro Barbaccia. I'm a physician and serve as professor and vice chairman in the Division of Family and Community Medicine at the University of California in San Francisco.

In addition, I serve as geriatrician and coordinator of geriatrics teaching for the division's affiliated and sponsored family practice training programs, which have the responsibility of training approximately 115 residents at any one time.

The division also provides clinical training in family medicine to all medical students in their last year of medical school.

My professional activities include chairmanship of the Chronic Illness and Aging Committee of the San Francisco Medical Society and membership in the Long-Term Care Review Committee of the California Medical Association.

I also represent the medical society on the county's adult day health planning council.

At this hearing we are addressing issues around the gaps in services relating to long-term care and ways in which these gaps might be closed; that is, what long-term care policy in the United States might include.

Those of us who have been directly involved in the care of the elderly or who have engaged in research around health services for the elderly, specifically long-term care, realize that health care policy in the United States stresses fundamental differences in the health care for the poor, on the one hand, and for the middle class and upper income segments of the elderly on the other.

We have medicaid, medicare and combinations of the two as though the health problems of the poor elderly and other sectors of the elderly population are fundamentally different.

In fact, those who are relatively affluent receive medicare payments for much of their medical care and supplement this in ways so that their medical and social needs are met because of their ability to pay.

The poor in California generally have two payment mechanisms available, medicaid and medicare and what the latter doesn't pay, very often the former will pick up, while still leaving some services inadequately covered such as acute and long-term in-home services, because of the lack of enthusiasm of medicare and medicaid to pay for such services.

Middle income families, however, aren't generally covered by medicaid and must pay out of pocket for deductible and coinsurance charges associated with the health-care benefits covered by medicare.

Those who can afford it buy insurance riders to medicare so that these out-of-pocket expenditures are also covered.

Many of the lower, middle class elders, however, are not able or are unwilling to pay the monthly cost for such medical insurance beyond paying for part B.

This is reflected in national medicare utilization data which indicate that the lower and middle income groups of elderly use fewer hospital and skilled nursing facilities days per year than do the more affluent. To me this is a gross injustice.

Suffice it to say that the cost of deductibles and coinsurance factors is a problem for many elderly. It must also be emphasized that medicare is an acute illness payment mechanism. It does not cover long-term care as such, while medicaid pays for acute and long-term care for the poor elderly.

Long-term care is not considered real medical care, but rather custodial or social care or at least a mixture of the two.

Thus another major difference that we make in services for the elderly is that we consider some services as medical, such as acute hospitalization, and will pay dearly for using and reusing an acute hospital as a place of care for medicare and medicaid patients whenever medically necessary.

Some services, however, are considered social, as in the case of many in-home services. Those of a homemaker for instance, and thus we are extremely parsimonious with medicare and medicaid funds that might be used for personal or social care. Yet, such personal care services provided under the supervision of a home care nurse often permit early discharge from the hospital and when used judiciously and over time can serve to prevent rehospitalization.

The dilemma that we have created for ourselves around services paid for by medicare and medicaid is that we must fit them into a medical model of care, that is, they must be strictly medical and not considered social in any way, such as in the case of personal health services or maintaining a household together during a time of crisis.

Services provided during convalescence after an episode of acute hospitalization for recurrent episodes of uncontrolled congestive heart failure are too often considered social services by medicare and medicaid and if not provided by the family and/or friends, may not be paid for and thus may not be provided.

In essence, even though most medical problems experienced by the elderly are chronic health problems or acute illness episodes superimposed on chronic conditions, we insist on stressing payment only for acute care in hospitals, skilled nursing facilities, in the doctor's offices, or limited care at home as though these services are not components or were not components of long-term care for a chronic illness, such as congestive heart failure.

In addition, by separating medical care from social care, we behave as though the two are clearly separable. The prospect for paying for social services is approached with great disdain.

It is important to realize that most elderly reside in their homes and that only 5 or 8 percent reside in long-term care facilities such as nursing homes. Also, most long-term care health and social services required by the elderly are provided by family members and/or friends and neighbors.

This is true even in the instances of services required during convalescence after an acute episode of illness for which hospital care is required.

In a study recently completed by our research team at UCSF, results indicated that where family exists to provide care, most need social and health care services, are actually provided by them, while a very small but important portion of care is provided by health care providers such as nurses and physical therapists.

These latter services, which are considered primary care in-home services by medicare and medicaid, are paid for only if they are medically necessary and if medical necessity exists, yet by themselves could not possibly sustain an elderly person at home if family members or friends were not available to provide concurrent personal care services, considered social services by the funding mechanisms.

While there is reluctance to pay for either short- or long-term in-home services, either through medicare or medicaid, numerous research demonstrations paid for by State and Federal Government and others have indicated the effectiveness of in-home services in preventing hospitalization and/or decreasing length of stay in hos-

pital and preventing, in many instances, long-term institutional care as in nursing homes.

A recently concluded study by the Visiting Nurses Association of San Francisco demonstrated the effectiveness of monthly or bimonthly assessment or monitoring visits of nurses to chronically ill patients at home in reducing the total days of acute hospital care required by a group of 150 patients studied over a 1-year period.

The periodic visits, although decreasing the use of hospital care, are generally not felt to be medically necessary, since specific acute episodes of illness justifying them are not present.

Such monitoring visits are felt to be a part of long-term care. Medicare and medicaid would not reimburse an agency for providing such visits even though they reduce high cost services.

Recently, several home care agencies in San Francisco came to the Chronic Illness and Aging Committee of the Medical Society, which I chair. They indicated that the medicaid field office was approving many fewer in-home services than seemed reasonable to the professionals in the agencies.

After gathering data which indicated that the problem of nonapproval for requested services was indeed widespread, a meeting was held so that the providers and payers could discuss the matter. It was felt by those approving services that too frequently patients who were not completely housebound or that those who could be transported to the physicians' offices were receiving in-home services.

In-home care, therefore, was felt to be medically unnecessary.

Yet these are the very services that prevent or reduce rehospitalization and institutionalization. This approach to me seems rather pennywise and pound foolish.

I feel that medicaid and medicare policies should be changed to permit long-term care support for families of the chronically ill and elderly, since they, after all, provide most of the sustaining health and social long-term care.

It is my conviction that health care policy should accept as desirable in-home, long-term care of the elderly whenever possible, because this is what most of the elderly want and this is what actually occurs.

But instead of denying families, frequently elderly spouses, adequate care and support and respite when necessary by denying allowances for home care, additional funding mechanisms through medicare and medicaid must permit adequate long-term care at home for those individuals who can be safely cared for at home.

Of course, those who cannot be taken care of at home must be cared for in nursing homes and other facilities.

Assistance with paying for long-term care should be available for the poor and the middle class elderly so that the degrading process of spending down to the level of a pauper is not necessary before public funds are available for long-term care services.

New organizational models currently being demonstrated around the country and as represented in San Francisco—we've heard and will hear about On Lok, Mt. Zion, French Hospital, so-called social health maintenance organizations and preferred provider organizations or variations of these—can provide the full gamut of medical

and social services for the elderly from housing through acute hospital care.

Through prepayment or capitation funding mechanisms and medicare and medicaid waivers, acute and long-term health and social services can be available based on patient needs and at the level of care required.

Internal mechanisms can serve to secure the appropriate amount and level of quality assured care without having to seek approval of external regulators before providing each separate service.

I personally feel that such innovations are both visionary and mandatory as the numbers of the frail elderly increase.

These mechanisms, however, must allow wherever possible care providers, including physicians long known to patients who join such organizations, to continue to serve them.

Additionally, such mechanisms should allow the elderly who live at home and wish to remain at home to receive home care as long as is possible and is feasible.

I'm grateful for having been given this opportunity to speak to you today on this important topic.

Mr. PEPPER. Thank you very much, doctor.

Now we'll hear from Dr. Gee.

STATEMENT OF DR. WILLIAM GEE

Dr. GEE. Mr. Chairman, members of the panel, ladies and gentlemen.

My name is William Lawrence Gee. I'm a practicing dentist in San Francisco's Chinatown. I'm also a member of the San Francisco Commission on the Aging, chairman of San Francisco's Adult Day Health Planning Council, and the vice chairman of United Way of San Francisco Bay Area.

But it is in my capacity as president of the On Lok Senior Health Services that I'm speaking to you.

On Lok is a nonprofit community based organization established in the early seventies to serve the needs of the sick and the impaired elderly of San Francisco's Chinatown North Beach area.

Over the past 12 years, On Lok has had the privilege through research projects, demonstrations, and waivers to develop and refine a long-term care system which helps the older impaired person remain in the community.

In 1972, On Lok developed a day care center. By the end of 1974, that day care center was California's first medicaid waiver demonstration of what now is a statewide adult day health service program.

On Lok expanded its community service from 1975 through 1978 building upon day health and including in-home services, social day care, and housing.

In 1979, On Lok began a new demonstration now known as the Community Care Organization for Dependent Adults or CCODA.

With medicare waivers from the Health Care Financing Administration and research and development funds from the Office of Human Development Services and the Administration on Aging, On Lok developed a comprehensive and long-term care service system.

So for the past 4½ years, On Lok has provided all the health and health-related services from transportation to hospitalization to approximately a population of 300 older people so frail that they are certified by the State of California as being eligible for placement in a skilled nursing facility.

Medicare reimburses On Lok for all of its delivery costs, and On Lok's professional multidisciplinary staff has the freedom and the flexibility to provide the services needed without regard to normal reimbursement requirements, restrictions, or constraints.

Our expectations for On Lok are realized and even surpassed.

First, On Lok found that indeed many people can be kept out of nursing homes. Today, less than 3 percent of On Lok's population actually resides in a skilled nursing facility. This is less than the national average for the total population of over 65 years of age.

Second, and more important from medicare's perspective, hospital days have been reduced.

Since 1978, On Lok has been able to reduce its percentage of hospital days from over 2 percent to now just over 1 percent of total days.

This rate is comparable again to hospital use by the general medicare population, both healthy and frail.

Third, community services were considerably increased. Nearly all of On Lok's participants attend a day health center at least a few times a month and some attend daily.

Many receive in-home services.

And fourth, the bottom line costs were favorable.

Although community service costs were high, savings on acute hospitalization on skilled nursing facilities offset these high costs.

On Lok's total per capita costs now are $1,220 per month which is only about 85 percent of what medicare and medicaid usually pay for such frail persons.

There are a number of points that I would like to make based upon On Lok's experience.

Above all, long-term care can and should be a part of the community's health service delivery system. It should be community based. Persons should be able to receive services while remaining in their own home and in their own community.

On Lok's philosophy from the very beginning has been to help the older person remain at home as long as it is medically, socially, and economically feasible.

On Lok has found that while some people need hospital and skilled nursing care at some time, over all, much of the skilled nursing placement and some of the hospital placement can be reduced.

Community based means community controlled. The long-term care system needs to reflect and be scrutinized by the community.

On Lok's door, for example, is always open.

My next point is that services need to be integrated to meet the needs of the long-term care population.

The frail elderly adult has multiple interrelated needs. Medical problems, functional limitations, varying degrees of confusion, and disorientation are the norms rather than the exceptions.

Services funded by different programs and delivered by many different providers are not an adequate response.

We have seen people going into hospitals because funding wasn't available for a portable meal.

Single-source access and controlled overall services is crucial. As service providers, we are concerned with providing the highest quality of care with the available resources.

As taxpayers and political realists, however, we must also address the problems of cost control and long-term care.

In the present reimbursement system, neither the consumer nor the provider has any responsibility for cost containment and as a result costs have gone out of control.

Risk-based capitation reimbursement which place the service provider at financial risk has been successfully employed by the health maintenance organizations, the HMO's, in dealing with the generally healthy, usually younger population. On Lok's experience shows that the same principle can be applied to long-term care with even greater success in controlling the cost and improving the quality of care.

Ironically, HMO-like programs serving the frail aged like On Lok's CCODA, do not qualify under existing Federal and State HMO legislation because they do discriminate based upon frailty.

My final point is that special attention must be paid to the plight of the middle income, long-term care needy.

The wealthy can buy whatever they need and the poor have medicaid to help meet long-term care needs. But those with small savings or income have to lose everything before getting adequate care.

The present long-term care reimbursement system most abuse the middle class who typically shoulder the biggest tax burden during their working days.

Medicare insures against acute hospital bills, but with this middle-income group, the truly acute problem is the high continuing cost for chronic care.

A number of pieces of legislation have been proposed to address the long-term-care problem of the middle-income group. Among them are part D of medicare. I understand part C has been preempted for dentistry, so we will move over to part D instead.

A separate insurance program for long-term care services. Expansion of medicaid eligibility to include the middle income in need of long-term care and integration of medicare, medicaid, and long-term care social services into a single authority.

For example, perhaps, title XXI. What is needed urgently is a national long-term care policy which guarantees every individual the right to needed health and health-related services not only in the interest of the individuals, but to control public expense.

The present patchwork of reimbursement only leads to uncontrolled costs.

November 1, 1983, On Lok began the fourth phase of the development of its long-term care system. On that day, On Lok became the first program in the country to assume full financial risk for the delivery of all health and health-related services exclusively to a certified frail population.

Through assumption of risk, On Lok has explicit incentive to control costs. Medicare and medicaid now pay On Lok a monthly

fee that is less than these programs normally cost for this population.

So, cost savings are already guaranteed.

Nonmedical participants now pay their share of costs for services not normally covered by medicare.

On Lok continues to have the freedom to serve individual needs rather than reimbursement constraints and realize the financial risk is the price of this freedom.

Our demonstration was authorized by an amendment to the 1983 Social Security Act for which I would like to thank members of this committee and others who supported us.

While On Lok has indeed been fortunate in having the opportunity to develop its model long-term care system, On Lok is not unique. There are many other good demonstrations going on in this country and many other providers across the Nation have approached On Lok in search of a similar opportunity for better serving the people they care about.

Therefore, we urge Congress to support the development of innovative systems of long-term care to address the dual concern of quality and cost control.

Ongoing medicaid demonstration authority as granted in section 2170 of the 1980 Omnibus Reconciliation Act is a step in the right direction, although there are some implementation problems.

On Lok has worked with the California Legislature Subcommittee on Long-Term Care and know well their interests and barriers they face in establishing long-term care programs in the State.

Congressional support is needed to see that the intent of 2176 is realized at the State level and that similar medicare waivers are enacted.

Furthermore, we must look to these demonstration programs not as time-limited experiments that will be started, stopped, and studied by its ongoing evolving system that continuously strives to improve the long-term-care services and reduce costs.

We must find new, better, and more cost-effective programs to serve the aged in need of long-term care and extend these innovations into policies through legislation.

We must caution, however, that these programs do not develop in 1 day, 1 week, 1 month, 1 year, or even 3 years. They take time.

Medicaid, medicare, the States, and Congress must work together with providers and consumers to develop more equitable and effective systems of service for our frail aged.

It is time for action and we offer you our assistance and I thank you for listening to me.

Mr. PEPPER. Thank you very much, Dr. Gee.

We'll finish the panel and then we'll open for questions.

Mrs. Trager, we welcome your statement.

STATEMENT OF BRAHNA TRAGER

Ms. TRAGER. Members of the panel, I am Brahna Trager. I have spent all of my professional life in health care programs for the chronically ill, the physically handicapped, and for people who need long-term care. I have worked as an administrator of our State crippled children's program in California, as the executive di-

rector of a home health agency for long-term care, and as a special consultant to the Special Committee on Aging of the U.S. Senate. I am currently coediting a journal which is related largely to long-term care and to home care.

I will be talking mostly about home care in this presentation today.

The current persistent preoccupation with the cost of health care in the United States has produced some questionable reactions. This is particularly true of health care for the older population.

The impression that rapidly escalating costs of health care can be controlled only by reducing the accessibility, quality, and quantity of care provided to older people is a dangerous misapprehension.

For the older population, the major issue is the need for acceptable resources for long-term care.

Cost containment and the maintenance of optimum health must be a joint objective, and both depend upon a system of reliable health care measures which require a range of services and options adapted to a variety of needs over the long term.

The problem of long-term care is a label which covers absence of choice, care of poor quality, care which is inappropriate and limited or absent resources.

There has been less interest in finding ways out of the long-term care dilemma than there has been concern with protection of an industry.

At the present time, older people are being admitted to long-term-care institutions from hospitals with minimal attention to acceptable planning.

They are being cared for by overburdened families without recognition of the fact that such strains will lead inevitably to the long-stay institution unless help is provided.

They are frequently alone and without care of any kind until the long-term institution becomes a final solution.

Few of these arrangements represent the choice of the person most involved.

This situation has been reviewed repeatedly since the enactment of the medicare-medicaid legislation. The solution most frequently referred to has been the development of alternatives to institutional care, and of these, home health services have received the most attention verbally, at least, and always with the provision that such services must be cheaper than institutional care and that home-health-care services utilization must not entail add-on costs to the rapidly escalating expenditures for nursing home care.

The arguments in favor of a system of home health services have been enumerated repeatedly. There is strong evidence that older people dislike institutions and prefer to remain at home.

There is evidence that institutional placement may present important health risks.

Home health services have the advantage of great flexibility. They can be adapted to changing individual and family needs. People who are alone as well as those with families can be maintained for long periods of time in their own setting which is in itself a factor in maintaining health.

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It is, therefore, surprising that, except for a handful of programs in the United States, home health agencies do not provide long-term care.

The discouraging record of home health services development and utilization has also been reviewed on numerous occasions. They are not available in even minimally significant numbers. Large areas of the country have no services at all. Most certified agencies have very limited capacity, and the service range they offer is not adaptable to people with long-term care needs.

The most important problem is presented by eligibility and reimbursement constraints imposed by public regulations and reimbursement policies.

Public policy in long-term care has not only favored the institution, it has made any other choice almost impossible.

A further major factor in this situation has been the narrow approach to funds for the development of home health services.

Public funds have been substantially available for nursing home development. They have not been available for home health services development.

There are 18,000 nursing homes in the United States, most of them proprietary and reimbursed from public funds. There are approximately 4,000 certified home health agencies in the United States primarily dependent upon funding from voluntary sources and strangled by difficult utilization requirements.

These limit services to acute care in relatively infrequent circumstances provided by professionals whose skills are rigidly defined, and by paraprofessionals who functions are limited to nursing assistance.

Long-term care has different requirements. It must certainly be health care, but there is a large component of the services which is related to restoration and maintenance and in these the homemaker functions play an important part.

Since these are not reimbursed, people may go into long stay institutions because relatively simple, but essential, support services are not available to them.

The public policy expressed in this system is based on the assumption that long-term care is entirely custodial and that there is no room in long-term care for improvement or stabilization or improved physical and emotional well-being.

These objectives are in fact achievable and with good long-term care, the personal environment can be a powerful factor in their achievement.

If a different strategy is to be undertaken, it must be in the direction of health measures which work. Cost capping is not a health measure. Preferred provider status is not a health measure. Diagnostic grouping is not a health measure.

It is questionable whether any of them will improve the health status of the population.

A shift in emphasis in the direction of something more than short-term acute care or long-term custodial care does offer that possibility.

Such a strategy requires in public policy a frank endorsement of a system which will support services more appropriate to the health status of the individual.

In long-term care, this will mean an endorsement of care outside the institution and in the community in order to create a better balance between the two methods.

Care which is based in the community will involve action in several directions.

First, a rational rearrangement of the present confusion in State and Federal funding sources and eligibility requirements.

Second, planned development of home health services in order to achieve equity of access and service range throughout the United States.

Third, realistic changes in home health services certification and eligibility requirements in order to achieve a better matching of the needs of the consumer of long-term care.

This will involve provision of a broader range of professional services and redefinition of the concept of skilled care as it is applied to long-term care.

Fourth, the requirement that all home health services require paraprofessional care which provides assistance with activities of daily living and environmental maintenance as needed as a part of any reimbursed plan of care.

Fifth, redefinition of the concept of part-time intermittent care in order to allow for variation in the intensity of need.

Sixth, an aggressive approach to preventive care in high risk groups using established methods of outreach, health supervision and health education based in health departments and health centers.

Seventh, greater emphasis on hospital discharge planning with special attention to care in the community. The requirement that there be at least one after care call to discharged patients who are at risk would be an effective adjunct to discharge plans.

Eighth, implementation of the concept of the community network, with the development of such services as adult day care, meal services, special needs transportation, and introduction of the many electronic security and monitoring devices now being used in home care programs in Europe..

Ninth, serious attention to the range of innovative housing arrangements which are being developed abroad and which increase the feasibility of home care planning.

It is no longer news that planning for the needs of older people in the area of long-term care has been seriously deficient in the United States.

The need is not the problem. The problem is our indifference to the need and our unwillingness to take the necessary steps to meet it.

Home health services are in effect a resource which may potentially provide older people with what everyone looks forward to achieving, a decent life and a decent environment that is a result of personal choice rather than an imposed necessity.

It is certainly not an unreasonable hope and could certainly be met with reasonable measures.

Thank you.

Mr. PEPPER. Thank you very much, Miss Trager, for your excellent statement.

Unfortunately, we are having a problem with time.

I had the pleasure of meeting Dr. Estes last evening and I wish I could hear all of her statement, but I'm going to ask her——

Do you have an extra copy that you can give me that I can take with me? All of these statements, of course, will be fully carried in the record, which we will very carefully study, because you are right on the beam in developing ways by which we can provide long-term care to the people of this country. Dr. Gee, your system, the On Lok system, which is substantially the HMO system, is the one that seems to us the most inviting.

Dr. Estes, could you put your statement in the record and will you summarize it for me? I want to hear from you and if you'll give me a copy of it, I'll take it and read it on the plane.

STATEMENT OF CARROLL ESTES

Dr. ESTES. Thank you, Mr. Chairman.

I am a professor of sociology at the University of California in San Francisco in the School of Nursing, and I am a director of an Aging Health Policy Center.

I have served on the California Commission on Aging and have been a consultant to the U.S. Senate Special Committee on Aging for a number of years.

It is a distinguished pleasure to be here and what I would like to do is to just emphasize quickly some of the points that are in my written testimony.

I think that to consider the long-term care problem, we must consider the other half of the coin as well, which is the acute care problem because we cannot resolve, we do not have the resources to resolve, the long-term care problem, without addessing the cost issues within the acute care sector.

The difficulty is, as you have pointed out, Mr. Chairman, very clearly, not that medicare and medicaid are problems, but that of necessity. They were required to buy into an existing system which contained highly inflationary incentives for cost rises. So the result is that we have replaced the goal of providing access to needed services to for the poor and elderly cost containment.

I raise the question: Is the administration correct that we have to accept a tradeoff between access and equity in the desire to contain costs?

My testimony stands on the proposition that we do not have to accept such a tradeoff and that in fact economic efficiency and a comprehensive equitable long-term care system are compatible.

The solution lies in a comprehensive rethinking of the system, not in trying to further fragment an already fragmented system.

While I've talked about the issues in the written testimony of access, cost, quality and continuity of care, these are issues that can be dealt with if we view the problem from the standpoint of the consumer. They cannot be resolved by applying the economic theories of price competition and market reform to illness, caring, and compassion.

It is time, Mr. Chairman, that our political leaders quit listening to economists and started listening to sick people.

In our research, we have been looking at the impact of current policies on both service providers and the elderly, and I can tell

you that the present policies penalize the sick elderly and shift more and more of the cost burden on their shrinking pocketbooks largely in the name of competition.

What can we do? We need access to a full range of services within one uniform, comprehensive system, and my suggestion is that we need to give very careful attention to what the Canadians have done.

In 1971 they were in a similar position with extremely high escalating health care costs, and they have invoked since then a universal national health insurance program including long-term care, at a cost that is far less than our fragmented and inadequate system.

And how have they done that? They have done that by using two strategies. They have used global budgets, which are negotiated budgets for hospitals on a predetermined basis, and they have used negotiated fee schedules for physicians.

The Canadians have a service system that does not leave 26 million people out of health care coverage as our current system does.

It is a system that is age-integrated and service integrated.

In terms of the current hospital cost containment, there are three strategies that are being discussed.

One of them, of course, is the hospital reimbursement policy changes that the administration is now beginning to implement through DRG's and other mechanisms.

But my point would be here that, unless we have cost containment mechanisms that involve all payers, not just medicare, that involve hospitals and physicians and all service providers as well as Blue Cross, private insurance, medicare, and medicaid, there will be cost-shifting, and ultimately the elderly will pay the highest price.

Again, I would point to the Canadian experience which has successfully constrained costs for health care in comparison to the United States.

U.S. costs were approximately the same then. Now, however, U.S. health-care costs are approaching 10 percent of the GNP and Canadian costs approximate 7.9 percent of GNP.

Again, I would emphasize that the all payer issues are very important.

Another approach, of course, for cost containment has been referred to as the health maintenance organization concept.

We are fortunately in the position, as Congress is now considering legislation, of knowing that there is growing evidence that it is possible to provide alternative community-based care at lower cost than institutional care. What is needed is Federal encouragement not just for demonstrations, but to continue the successful alternative models on a permanent basis.

I would urge you to consider the concept of the social health maintenance organization for long-term care. The SHMO's essentially adopt the same concept as the health maintenance organization, but include the full range of social- and community-based services that are needed.

The third approach to cost containment—cost shifting to the consumer—is suggested by a number of economists, particularly the precompetition health strategists.

In considering this approach, it is very important to note that this strategy will result in inequitable sacrifices among different members of the population. Escalating health costs that are now exceeding $14,000 a year out of pocket per elder, estimated for 1983, are extremely burdensome, particularly for minorities, for women and other low income individuals. These health care costs comprise very high proportions of their incomes, proportions which the table attached to the testimony shows goes up to 29 percent of the annual income for certain groups, in terms of the incurred out-of-pocket health costs.

The cost shifting and cost sharing approach is disproportionately bad for women and minorities and the poor, particularly since their health tends to be worse.

The increased copayments and deductibles strategies also increase not only out-of-pocket payments, but of course they increase the number of people who cannot buy part B medicare physician coverage, and then increase the number who cannot receive or purchase the Medigap insurance. These are mechanisms that further increase costs and inaccessibility to the aging.

I will close with the major point in my testimony which is to say that there is a link between solving the crisis in medical care costs and the crisis in the need for the long-term care of the elderly.

Comprehensive reform in the entire health care system is needed, rather than these stopgap measures which penalize those who need medical care the most—the poor and the sick.

We must challenge our basic complacency about the dual policy in health care, our separate systems of financing and administering acute care from that for chronic care.

The patient's needs certainly are inseparable for him and the combined effect of these separate policies and systems of care tend to be financially devastating.

It is a myth to think that the hard-working middle class are going to have an easier time in old age than the poor, particularly if they are sick. The middle class will ultimately receive welfare medicine unless current policies are altered. Even for individuals on moderate incomes, the expenses for chronic illness as well as for the acute care costs that are uncovered can lead to impoverishment.

All generations share a stake in resolving this problem. The solution, in my view, will not be abated by adopting the competition notions that a sufficient reduction of health care costs can be achieved with cost-sharing. There is no way that we can achieve a $300 billion savings for the medicare deficit by shifting the costs to elderly patients.

Not only that, the decentralization policies will not solve the dilemma, because the States are extremely hard pressed financially. Those here from State government can certainly testify to that.

Not only have the States experienced a taxpayer revolt, but they have had the recession. And they have had multiple taxpayer initiatives that have reduced their revenues. The States cannot increasingly bear the burden of health care and other costs for the poor.

My final point is that it is my firm belief that the equitable allocation and the distribution of the Nation's health care resources

cannot be reached without a vital Federal role and without national leadership.

It is increasingly clear that we will not have the range of comprehensive reform without concerted national leadership.

So let me close by recommending that the committee take the lead in developing a national policy that will give all people in the United States the same kind of universal comprehensive health coverage, including long-term care, that is already enjoyed by our less affluent, but equally hard-working, neighbors in the north, the Canadians.

Congress took a major step in enacting medicare and medicaid in 1965. Mr. Chairman, we need to go the rest of the way.

Thank you.

Mr. PEPPER. Thank you very much.

I'll ask the staff if I can get a copy of Dr. Estes' speech so that I can read all of it.

[The prepared statement of Dr. Estes follows:]

PREPARED STATEMENT OF CARROLL L. ESTES, PH.D.

Mr. Chairman, I am delighted to have the opportunity to testify before the House Select Committee on Aging on long term care and the elderly. I am particularly pleased, Mr. Chairman because of your long record of concern and leadership on issues of importance to the elderly. I would like to emphasize that the views that I am expressing are my own, although they are based on more than a decade of research with colleagues in the University of California on aging and health policy issues.

The dream of a national system of long term care services at an affordable price with access for those who need it appears more distant than ever. Replacing the dream is the specter of a monster—medical care costs are now escalating at three to four times the rate of inflation. The system accords low priority to the predominant health needs of the elderly—the need for chronic illness care in the home and in the community, and it provides instead high cost hospital care that is often inappropriate and unnecessary.

In order to examine the basic issues related to long term care, it is essential that we look at the other side of the coin—acute care as well. It is in resolving the problems of acute care that the answers can be found for resolving the problems of long term care. The health care cost crisis, as now being socially "constructed" by many of America's most powerful opinion makers, has been defined (erroneously, in my view) as a crisis in excessive consumer demand. Cries of the pending bankruptcy of Medicare are useful political symbols to justify drastic measures—eliminating services, beneficiaries and/or entire programs, while also shifting burdens and costs and responsibilities from government to individuals. The underlying ideology is that the scarcity of resources—rather than human needs—should govern public policy.

Further, there is no evidence that the elderly have misused either Medicare or Medicaid. Misunderstandings are created and public support is eroded for health programs when the crisis is defined as the fault of individual elder's choices to use too many health services. This version of the crisis is particularly interesting since it ignores the fact that it is the doctor who admits a patient to the hospital, orders laboratory tests and X-rays, writes prescriptions and in other ways determines 70 percent to 90 percent of medical care costs.

Blaming the elderly obscures the fact that rising health costs are directly linked—not to individual abuse of the system—but to the design and financing of Medicare and Medicaid, and to the economy and public policy choices—for example, unemployment (reduces payments in); inflation (accelerates payments out); and revenue losses through tax cuts have seriously squeezed health programs.

The abandonment of the goal of access (providing medical care where it is needed), in favor of the goal of cost containment brings us squarely to a critical question: Are cost containment and equity inevitable trade-offs? My personal view is that the trade-off proposed by Administration policies and conservative economists between cost containment and equity of access is a false and politically motivated one.

Some of America's most powerful opinion-makers would lead us to believe that we are faced with an "either/or" choice between costs and equity in access that we must accept like good medicine for the nation's ailing health. As a challenge to these ideas, my testimony stands on the proposition that economic efficiency and an equitable, comprehensive health system are not incompatible ideas. The solution lies in a comprehensive approach to health care, not in trying to further fragment an already fragmented system.

The crisis atmosphere is fertile ground for forced and unnecessarily harsh policital choices that erode basic entitlements. However, I believe that we can afford to meet the goal of the President's Commission on Ethical Problems in Medicine and Biomedical and Behavioral Research—the "ethical obligation to ensure equitable access to health care for all" (U.S. President's Commission, 1983, p. 4).

WHAT DOES THE "SYSTEM" OFFER TO THOSE WITH CHRONIC CARE NEEDS?

Given current health policy, those needing long term care will be faced with a system of restricted access, high costs, often questionable quality, and lack of continuity in care.

1. Access.—Obtaining long term care is itself a problem. The wide variety of services and providers makes it difficult for individuals to determine what is available, needed, and appropriate, as well as how to obtain reimbursement. Once individual needs are determined, access to services depends on either having private financial resources to be able to pay directly out of pocket for needed services, or qualifying directly for Medicaid because of extreme poverty or by "spending down" into poverty to become eligible as medically needy. The costs of institutional long term care are often borne by consumers without benefit of insurance: 40 percent is currently paid by private consumers out-of-pocket, while insurance payments and charitable contributions account for only three percent of all private nursing home expenditures (Gibson and Waldo, 1982).

Different federal statutory requirements and state policies compound the difficulty with multiple definitions, coverage, requirements, and reimbursement methods. Medicare pays for most hospital and physician services but excludes most nursing home and long term care services, primarily for those aged who can be rehabilitated and whose care is determined to be medically-related (for example, personal or homemaking services are not covered).

Medicaid is the primary payor of nursing home care, paying about 90 percent of all public funds spent on long term care—but for Medicaid eligibles only (U.S., Senate, 1982). Restrictive Medicaid eligibility criteria pose barriers to access; and eligibility policies vary substantially from state to state, as does service coverage (Scanlon, Di Federico and Stassen, 1979; U.S. HCFA, 1982). Although Medicaid is less restrictive than Medicare with regard to home health services, only two percent of Medicaid budget supports non-institutional health services such as home care since most states have limited their coverage as Medicaid does (U.S., HCFA, 1982). It is far easier to obtain Medicare and Medicaid benefits for hospital and nursing home care than for community-based or home care.

Many people who require some form of long term care, particularly noninstitutional care, often do not receive needed services. A large proportion of noninstitutionalized elderly people are cared for by family and friends—often inadequately because personal care, home health care, and housing needs cannot be met by community services. The Congressional Budget Office (U.S. CBO, 1977) estimates that up to four million adults will have unmet needs for home-based services by 1985.

The primary barriers to access are two fold: (1) the unavailability of public or private funds to pay for long term care because they are allocated to acute care, and (2) the lack of alternatives to institutional care in most parts of the country. While many long term care projects have been developed with demonstration grants and some states such as New York, California, and Massachusetts have been leaders in the development of alternatives, such as adult day care, the supply of such programs continues to be inadequate.

Access to nursing home beds is another problem. The supply varies from 23.9 beds per thousand elderly in Florida to 118.5 beds per thousand in Nebraska (U.S. NCHS, 1982). Medicaid recipients and the severely disabled have particular difficulty finding nursing home beds where reimbursement rates are lower then the private payor rates (Scanlon, 1980; Harrington, 1983). In many places, homes select private paying and light-care patients. Thus denying beds to public paying and "difficult" clients. As a result, some patients who should be in nursing homes are backlogged in acute care hospitals at a higher cost to Medicaid, while others who could reside outside of nursing homes may be placed in them due to lack of community based alternatives.

2. Costs.—The financial burden of institutional long term care costs to individuals and government is very modest when compared to what is spent for hospital care and trivial when compared to what is spent for unnecessary military hardware. Between 1971 and 1981, total expenditures for nursing home services rose 332 percent and the annual growth rate was 17.4 percent between 1980 and 1981, only slightly less than the growth in hospital expenditures (Gibson and Waldo, 1982). As the primary source of funding for long term care, Medicaid spent $12 billion in 1981 on nursing home care, 88 percent of all public expenditures on such care and half the total national nursing home bill (Gibson and Waldo, 1982). The financial burden on users—individuals, spouses and their families for skilled nursing care averaged $12,200 per year in 1981, although the median aged family income was only $14,335 (U.S. Senate, 1982; La Jolla, 1982). Many nursing home patients receiving Medicaid (as many as 48 percent in 1976) were not initially poor but depleted their resources so as to qualify as "medically needed" (U.S. CBO 1977).

The traditional bias in favor of institutionalization, that is relfected both in statutes and in practice, is a major contributor to the current cost of long term care. Less than 2 percent of total Medicaid expenditures are spent on community-based long term care services, in contrast to 40 percent spent on nursing home care (U.S. HCFA, 1981a; Gibson and Waldo, 1982). Further, the CBO (1977) estimates that between 10–20 percent of patients in skilled nursing facilities and 20–40 percent of those in intermediate care facilities do not need the level of care provided by those facilities and that they could be cared for with a less intensive level of care, or outside of institutions, at less cost. Other estimates suggest that up to 50 percent of the institutionalized patients could be cared for in less restrictive settings, depending on the criteria of need which are used (U.S. HCFA, 1981b; U.S. Senate, 1977–78; U.S. NCHS, 1979a).

3. Quality.—The quality of care in the present long term care system is uneven and often poor. The fears of institutional placement by the aged are justified in part by the undesirable conditions in many nursing homes. Abuses have been documented, and staff shortages are exacerbated by an overreliance on untrained or unlicensed personnel (Vladeck, 1980; US. Senate, 1974–76; U.S. GAO, 1979). These problems along with the lack of privacy, the impersonal atmosphere, the loss of family and social relationships, and the resulting deterioration of morale, make institutionalization the last resort for the aged and disabled (U.S. HCFA, 1981b). For many of the severely impaired elderly, however, the nursing home is the most appropriate place for care and we should do everything that we can to have that care competent and compassionate. Regulatory initiatives by federal and state governments in the 1970s had improved the quality of nursing home care. However, the de-emphasis on enforcement of even minimal standards by the Health Care Financing Administration must be a cause for grave concern (Hughes, K., 1983). Who else can protect these individuals if their own government abrogates that responsibility?

4. Continuity of Care.—The aged and disabled face a complicated and confusing service system in which it is difficult to coordinate a comprehensive package of non-institutional services (Harrington and Newcomer, 1982). Services are delivered by a variety of government and privately funded health and social service programs and by many different kinds of community and private organizations. Public agencies often purchase services from the voluntary and private sectors. While increasing the variety and flexibility of programs, the proliferation of agencies further fragments the delivery system and weakens accountability in the service network. In addition, there is fragmentation of services for different population groups, particularly between the aged and the disabled.

This fragmentation of funding and service agencies complicates the potential for access to a contiuum of long term care health and medical services. Thus, the responsibility of finding and gaining access to appropriate support rests primarily with the patients themselves and with their families—an often unmanagable task. The result frequently is inappropriate placement, failure to obtain preventive care, and overall cost inefficiency.

What can be done? Let me begin with a set of principles to guide the development of a comprehensive long term care system.

BASIC PRINCIPLES OF A COMPREHENSIVE LONG-TERM CARE SYSTEM

An adequate system of long term care should include seven basic principles:

1. First, it must be comprehensive including a full range of health and social services covering the continuum from community based care to institutional care.

2. Second, it must be linked with other health and social services as well as acute care services, including hospital care and physicians services. (Thus, it must not be separated into its own long term care closed system.)

3. Third, it must provide incentives for providers to keep costs at a reasonable level, to prevent overutilization and to promote the use of appropriate services. (One way to do this is to put providers at risk under capitated prepayment plans; another, is to have an effective system of regulations at the state level that includes hospitals, physicians and nursing home services.)

4. Fourth, it must have a financing system that provides protection from impoverishing individuals and that allows for combining private and public resources (e.g., allows individuals to buy protection before they become ill, perhaps through capitated prepayment plans, and provides coverage for the uninsured.)

5. Fifth, it must ensure open access to those who need the services regardless of ability to pay or other characteristics.

6. Sixth, clients must have access to the services regardless of age. While long term care (LTC) is predominantly used by older individuals, it is a system for those who are disabled of all ages. No adequate rationale for age segregation can be made in my view—but rather age integrated services are critical.

7. Seventh, it must include preventive and restorative services as well as treatment and illness management.

In order to meet these basic principles of a long term care system, however, we will need to resolve several very crucial problems.

Controlling the overall rate of increase in health care costs (e.g., through all payor regulation at the state level, global budgets for hospitals, negotiated fee schedules for physicians);

Developing pooled coverage (risks) for those 26 million (or more) Americans who are unable to afford health insurance;

Establishing incentives for non-hospital acute care services and for community-based long term care services;

Addressing tax revenue reform issues based on a reconsideration of tax equity (e.g., individual and corporate tax burdens) and the revenue needs of government;

Reducing unnecessary military spending where it takes away from essential domestic needs in income, health and social services.

As researchers, providers, policymakers, families and the concerned public, we are well aware of the high cost and low satisfaction associated with the delivery and organization of long term care. We know of the near desperate state of families who find themselves, in some cases, even forced to abandon their elders; we are informed of the hard working middle class retired couples who are forced into poverty when one spouse becomes seriously ill; we know the fragmentation and gaps in the delivery system; we understand that doctors may ignore or discount older people; we are afraid that policies aimed at increasing family responsibility will be a rhetorical cry for "do nothing." We are informed about the waste in professional capacity, the waste in human lives and the waste in material resources of the current system keyed to "helping" the long term patient by institutionalizing and impoverishing them into segregated warehouses for the poor and dying.

Over the past decade the notion of a "continuum of care" which would integrate social and health service systems in order to address both acute and chronic needs has been articulated and advanced in different ways. Despite impressive accomplishments in geriatric education, technology and service demonstrations, the truth is that our system performs far below its capacity—and far below that of our neighbor to the north—Canada.

The urgent need to DO SOMETHING is all the more urgent in light of government cutbacks. The monetary and human costs are enormous and involve all of us in moving in the direction of a viable long term care strategy, and not merely by piecemeal measures. However, where do we begin?

First, we must start with a basic commitment to the notion that chronic illness cannot be separated into certain specific kinds of providers and paid for on a piece work (fee-for-service) basis. Those with chronic illness not only need the Long Term Care services that I have described but also need hospital services, ambulatory medical services, drugs, eyeglasses, podiatry, dental, and many other services that are not traditionally called Long Term Care services.

Access to this full range of services within one comprehensive system is essential. But how are we going to get there? How have others gotten there? How have the Canadians managed to have a system of comprehensive universal national health insurance—including long term care at a cost far below that of our fragmented and inadequate system? While few of us need to be reminded about the primary issue of cost control in an age of austerity, I would just like to underscore that we must not

lose sight of the interdependency of the two systems of care, that is, chronic and acute services. We must have a system that is both age integrated and service integrated. Although an integrative approach to long term care issues and options goes against the current fragmented sources of funding we must begin to work together on these two fronts. Until we have effective cost control of institutional (especially hospital and nursing home) services, we are not going to have the capacity to move toward developing the kind of rational, comprehensive, health care system, including long term care we envision.

Numerous proposals for controlling health care costs are widely debated with an enormous amount of vested political and economic interests at stake. I do not intend to go into detailed explication of complicated formulas, but rather what I would hope to present today is a highlight of some important features of three proposed strategies of cost control—(1) reimbursement policies, (2) change in the organization of delivery and payment and (3) cost-sharing.

METHODS FOR CONTROLLING HEALTH CARE COSTS

1. Hospital reimbursement

Because there is general agreement that the rapid rate of increase of health care costs must be reduced. High priority is being given to hospital cost containment through altered reimbursement policies. Congress altered Medicare hospital reimbursement substantially in the Tax Equity and Fiscal Responsibility Act of 1982 and in the 1983 Social Security Amendments. In addition, the Administration has proposed further dramatic increases in patient cost sharing. While this piecemeal approach may reduce hospital expenditures in the Medicare program in the short run, many expect it will result in cost shifting to private third-parties unless policies are adopted to prevent that practice by hospitals. It is also likely to diminish access or quality of care for the elderly unless the Medicare cost containment policies are part of a cost containment effort that includes all payors. Unless the rising costs of health care are contained—across the board for hospitals, physicians and nursing homes and for all payors (Medicare, Blue Cross, commercail insurance, Medicaid and other third parties)—there will be a continued hemorrhage of medicare trust funds and this result in continued rising costs in services and the shifting of these costs to the aged. Medicare cannot be saved by incremental "Medicare only" type reforms, no matter how desirable. An "all-payor" hospital reimbursement system had been adopted in four states—New York. New Jersey. Massachusetts, and Maryland. Each state has taken a different approach to regulating Hospital payments (e.g., New York has established a per diem rate, New Jersey a per admission rate). I recommend that Congress adopt legislation requiring effective cost containment at the state level, and if this is not accomplished that Federal Regulatory policies would be put into effect.

An example of a method of all payor regulation, which reaches beyond Medicare-funded service, is global budgeting in which government sets limits on the annual hospital expenditure increases to a predetermined amount. Canada's experience illustrates what an effective method global budgeting can be in controlling hospital costs.

Since the early 1970's, with the exception of the U.K., Canada has been more effective than any other Western industrialized country in controlling health care costs. Prior to 1971, when Canada's publicly funded medical and hospital insurance program was fully implemented, health care expenditures had been rising more rapidly in Canada than in the United States (Marmor, 1982; Simanis and Coleman, 1980). Since 1981, however, health care expenditures have been contained to a remarkable degree. In 1971. 7.5 percent of GNP was attributed to all health care expenditures. In 1981. this figure was 7.9 percent. In 1982, it was approximately 8.2 percent of GNP. In the United States during the same period, health care expenditures rose as a percent of GNP from 7.8 percent to 9.8 percent to 10.5 percent. Canada has controlled these costs by instituting global hospital budgeting and negotiated fee shedules for physicians (on a fee-for-service basis) at the provincial level.

2. Change in the organization of delivery and payment

In addition to the federal-state role in setting limits on the amount reimbursed for health care, there is also the consideration of federal-state government offering incentives for the way in which health care is organized and paid for.

The optimal LTC system should be built on an incentive structure that encourages providers to control their costs. Prepaid plans are one means of doing this. Preferred provider contracts offer another.

One alternative that should be considered is a prepaid and capitated system that permits levels to be established in advance of service provision and that bases payment on each individual enrolled rather than on the units of services delivered. This would ensure that providers have incentives to keep costs below the rate provided. This has been a key feature of health maintenance organizations which generally have been able to reduce costs to the States where they have been utilized.

There are several long term care programs developed on this model, stressing social services. These have been called social health maintenance organizations (S/HMOs) and they are well worth your careful examination. The S/HMO combines a comprehensive delivery system with a financing system (prepayment) that controls costs (Diamond and Berman, 1981). S/HMOs provide a complete range of both social and health services from acute medical care to homemaker and chore services. They are modeled on Health Maintenance Organizations (HMOs) with the addition of long term care and social service benefits, traditionally not included in HMO plan benefits S/HMOs are financed with a payment system based on capitation rates (fixed in advance per individual) like the payments for HMOs. Clients enroll voluntarily and payments for enrollment may come from a variety of sources including Medicare, Medicaid, and private sources. Initial S/HMOs have been primarily focused on the aged but can serve blind and disabled population groups as well. Strong arguments can be made for offering enrollment to all individuals at risk of disability. S/HMOs are financially "at risk" in that they must provide all benefits for the fixed, prepaid fee. Since costs expended over revenues must be covered by the S/HMO, the system is designed to encourage cost-effective management of care.

3. Cost sharing

Let us turn now to the differential sacrifice demanded of the major pro-competition health strategy—namely, increased cost-sharing. Escalating health care costs and budget cuts significantly raised the proportion of costs personally shouldered by Medicare recipents. Recent policy changes have increased the fiscal hardship of millions of near-poor and poor elderly who are being called upon to bear the growing burden of their health care costs—costs that comprise 17 percent to 29 percent of the elderly's budget (except for older white men) and that now exceed $1,100 per capita in out-of-pocket expenses (and are likely to increase to $1,430 in 1983; Davis, 1982, p. 25). Out of pocket health care expenses are disproportionately borne by older blacks and women. The burden is especially high for the poor and the near-poor who are sick. These costs are sobering in view of the fact that the median income for individual elders in 1980 was $4,226 (Storey, 1983), and in view of the fact that the poor and minorities tend to be sicker.

FIGURE TITLE: "IMPACT OF DIFFERENT OUT-OF-POCKET HEALTH EXPENDITURES"

Medicare deductibles (the base amount one pays before care becomes covered) and copayments (the proportion of total charges payable by beneficiaries) have both increased dramatically in the past two years. The Part A (Hospital) deductible increased 27 percent between 1981 and 1982 (from $204 to $260), more than double the historical increase. Yet another increase has been incurred for 1983 (to $304). The medical insurance benefits (Part B physician services) annual deductible rose from $60 in 1981 to $75 in 1982.

When applied equally to all Medicare beneficiaries, the differential impact of these flat rate cost increases becomes clear. As a percentage of income, lower income elders bear a significantly higher proportionate cost for their health care than do higher income elders. For example, the Congressional Budget Office projects that "by 1984 noninstitutionalized persons with household incomes under $5,000 will have medical expenditures totalling 97 percent of their $3,659 average income, 18 percent of which they must pay out-of-pocket. Those in the highest income category * * * or $58,306 * * * will pay just over one percent out-of-pocket" (U.S. CBO, 1983, p. 21).

The increases in copayments and deductibles are expected not only to increase the out-of-pocket payments for the aged but also to: (1) increase the number of aged who cannot afford to purchase Part B Medicare coverage for physician services: and (2) increase the price of supplemental insurance so that many aged will not be able to purchase it, both of which will further increase costs and inaccessibility to the aged. The small increase in coverage that the Administration has proposed for catastrophic insurance would not offset any of these increased costs to the elderly for Medicare, since estimates that are only two percent of older persons would benefit from the catastrophic coverage (Harrington, 1983).

In summary, the import of my testimony concerning the link between the crisis in medical care costs and long term care for the elderly has been to recommend comprehensive reform of the entire health care system rather than stop-GAP measures which penalize those who need medical care the most—the poor and sick. Further, I would agree with the conclusions of the report from New York State Office for the Aging that:

"The Medicare program and its beneficiaries are a victim of our current health care system which fosters the use of costly, highly technical, and often unnecessary care. Rather than simply shifting a greater share of the cost of this system onto the elderly and other levels of governments, reform measures must be directed at changing the fundamental nature of our health care system. (P. 24, "Medicare: Analysis and Recommendations for Reform," N.Y. Office on Aging, September 13, 1983)"

CONCLUSION

Thus far public policies have addressed short-range approaches to long term care issues but if Congress or other public policy makers are to entertain the idea of fundamental reform, a long range perspective is needed.

It is my belief that the goal of an equitable allocation and distribution of the nation's health care resources cannot be reached without a vital federal role in health and aging. As state and local governments across the country devise ways to met the countervailing demands of taxpayers, providers, and equal health advocates, it becomes increasingly clear that long range comprehensive reform will not come without concerted national leadership.

As you are well aware, the Reagan administration's new federalism and decentralization strategy turns the nation's compass in quite the opposite direction. In framing a long term care strategy, then, Congress must consider the relationship between state-local government capacity to assume responsibility for the elderly (and particularly for the long term c..re policies for the near-poor and poor elderly) and the fiscal context within which state and local governments are operating, the interrelationship between state and federal economic conditions and policies and the real (and growing) revenue disparities across different states and geographic regions.

The myriad of state level cost savings strategies in health have not lead to systemwide reform. Our research demonstrates that, on the contrary, savings from direct cutbacks or from eligibility restrictions have not resulted in the transfer of money to social and community-based services (Estes and Newcomer, 1983). Often such savings (where they occur) merely enable state and local governments to keep pace with the overall inflation in medical care prices and the pressures on Medicaid generated by unemployment.

We must begin to challenge our basic complacency about the notion of a dual policy in health care. The United States has separate systems of financing and administration for those requiring acute care and for those requiring chronic care. The needs of the patient are inseparately and the effects of illness can be financially devastating. The idea that hard-working middle and upper class people will be spared the same indignity of welfare medicine in old age that the poor receive is not only myopic; it is a myth. Even for those individuals and families living on moderate and middle incomes, expenses for chronic or acute illness can lead to impoverishment.[1] Currently, private insurance and Medicare do not provide for long term care (LTC) coverage. All of us, as we reach old age are at risk of impoverishment without an adequate system of long term care financing. Who among us could afford the $50 to $100 a day for nursing home care or intensive home care, or $18,000 to $30,000 per year in costs for nursing home care for any extended period of time without losing our home, impoverishing our spouse and virtually forfeiting an independent and dignified future?

The demand for real long range solutions to the human and economic dilemma of long term care policy will not be abated by the political call for unequal sacrifice

[1] Medicare covers less than 44 percent of the elderly's medical care expenses and Medicaid aids primarily those in nursing homes who have exhausted their private resources. The average aged individual in the U.S. paid $1,436 in out-of-pocket expenditures in 1980. At the same time, the median income for older individuals was only $4,500 (in 1980), illustrating why many older people are unable to pay for health services, and particularly for long term care (LTC) services. This figure is likely to increase if the current proposals to further augment the costs to the patients in the Medicare program are adopted by Congress. When chronic illness lasts over a period of time, many middle class elderly individuals and families soon exhaust their resources and are forced into using public resources to pay for expensive care.

nor by piecemeal cost control schemes. Nor will the long-term care dilemma be resolved by the Reagan administration's decentralization strategy. Indeed, an important issue for long term care policy is the recognition that increasing decentralization of programs for the poor, aged and disabled fosters politically motivated, rather than need-based, priorities and allocations. The decentralized programs of medicaid and SSI supplementation have created wide variations in income and health eligibility and benefits for the poor, the elderly, blind and disabled across the states. Due to the stringency of eligibility in states, less than 50 percent of those below poverty are eligible for medicaid. Given the current structure of programs relevant to long term care, U.S. "national" policy is now comprised of multiple, variable, non-comparable policies and programs, that are different in different states.

Currently, options for alternative long term care benefits are heavily influenced by a state's willingness to underwrite the costs. We may recall that Reagan's initial New Federalism "swap proposal," which designated complete financial responsibility for long term care in the hands of state governments, was unanimously and vigorously rejected by the National Governor's Association. Our own studies of medicaid, focused on the 1982-83 period, show that most of the state medicaid policy changes in 1982 were cost containment strategies aimed at reducing the growth rate in program spending (Estes and Newcomer, 1983).

These studies further illustrate the vulnerability of the aged to capricious and complex Federal and State health and aging policies, as well as to broader policy considerations, such as cost containment and decentralization of programs from Federal to State and Local Governments. These policies have serious consequences for the elderly. In this period of inflation and perceived fiscal crisis, we expect an exacerbation of the already existing inequities among states in the eligibility and scope of services available to the most disadvantaged elderly.

A major question is whether or not particular long term policy goals and priorities should be determined nationally or left to the vagaries of state or local politics. Given the structure of current programs, a complete understanding of "national" policy on health care for the aged cannot be obtained without systematic examination of policies across states. The goal of such an examination should be to distinguish those responsibilities that are logically state and local in nature from those that are so significant and moral in impact that the inequities that could arise from so decentralized decision making must be prevented through the development of a single national policy.

Numerous proposals have been advanced concerning the need for a national uniform policy on long term care. Bruce Vladeck's proposal, for example, was to merge medicare and medicaid's long term care portion together into one single continuum of care system (Vladeck, 1981). The private out of pocket money spent on long term care in addition to the medicaid national long term care dollar is an enormous sum. If we can combine these separate public and private resources we may begin to build towards the development of a truly national health insurance protection for older people in this country.

Let me conclude, Mr. Chairman, by recommending that the Committee take the lead in developing national policy that will give all the people of the United States the same kind of universal comprehensive health insurance, including long term care, that is already enjoyed by our less affluent but equally hard working neighbors to the north—the Canadians. Congress took a major step in enacting medicare and medicaid in 1965. Mr. Chairman, we need to go the rest of the way.

Thank you.

Impact on different out-of-pocket health care expenditures on the mean income of various elderly subgroups, 1981[1]

1981 per capita out-of-pocket health expenditures of the elderly	$1,154
Percent of mean income for all older persons	13
Percent of mean income for older women	17
Percent of mean income for older Blacks	23
Percent of mean income for older black women	27
1981 per capita out-of-pocket health expenditures, less nursing home costs, for the noninstitutionalized elderly population	$834
Percent of mean income for all older persons	9.5
Percent of mean income for older women	12.5
Percent of mean income for older Blacks	16.5
Percent of mean income for older black women	19.8

[1] Source: New York State Office on Aging, 1983.

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Mr. PEPPER. I want to thank this distinguished panel, particularly, for your contribution. This is the kind of thing that we're concerned about.

What can we do to meet the challenge of this problem? You are giving us some valuable experience with On Lok there and other activities in which you have been engaged which will be very helpful to us. We want to work with Ms. Moorhead, Senator Mello, Director Ream and others to try to find the right answer.

What we're trying to do is to develop a consensus in America of the kind of program we should support and then mobilize, to carry our opinion to the other leaders in this country.

There are 26 million of us over 65 years of age. We don't have to come as supplicants on our knees asking public authority to recognize our needs. We have the right to vote and we have the right to express a meaningful opinion to the political authorities of this country.

We're speaking for the humanitarian cause of taking care of the needs of people—critical needs that are being neglected at the present time.

You've helped us to formulate our objectives and I am particularly grateful to you.

Do you have any other questions?

We simply have to go on, unhappily, but I'll ask Ms. Burton if she'll continue the chairing of the conference and allow any questions of this panel that you would like to ask and then there is one other panel that will be heard as soon as this panel is concluded.

I want to thank every one of you in the warmest way, all of you people who are here to encourage our efforts this morning, to tell you how grateful we all are.

By the way, is Mrs. Harmon in the audience?

I don't believe I see her.

Well, thanks again.

Thank you, Mrs. Moorhead.

Ms. MOORHEAD. Thank you.

Mr. PEPPER. Thank you, Senator Mello.

Thank you, Director Ream, and thank you very much, my colleagues, Mrs. Burton and Mrs. Boxer.

Thank you all and God bless you.

Mrs. BURTON. We are truly blessed to have this very fine Congressman, Chairman Pepper, here.

I would like to ask Dr. Estes. You said the very same—you used the same words as I did. I don't know whether you heard me or whether you were here.

Was this panel here earlier when I said we need a national health policy for all of our people? Did you hear that? I said that early, we're going to fight for it. It's been kept very quiet, but you know the administration does not favor national health care.

We're going to hope and pray, and with your help, maybe there will be a change.

We need that; there is no question about it. Canada is truly a model. Why we can't have it in this country, the only industrialized country in the world that doesn't have a national health policy, national insurance—socialized medicine is a terrible word—so I'm not going to use that, because some people get offended by the words, but this is what we're talking about.

It's a disgrace and it would be cheaper in the long run and I commend you for saying it loud and clear.

Thank you.

Dr. ESTES. Thank you.

Mrs. BURTON. Now, Dr. Barbaccia, do you agree with that? I'm putting you on the spot, I gather.

Dr. BARBACCIA. I think that we——

Mrs. BURTON. I would very much like to hear from you on that

Dr. BARBACCIA. I guess I would put it this way, Mrs. Burton, that I think what we need, after a very careful analysis similar to what Dr. Estes is proposing, is an American solution to the problem of providing care and paying for care for all Americans.

I'm not willing at this point to say that that should take one form or another, but I think that it would be very important to do the analysis that she's talking about.

I don't know if a British or a Canadian or a Swedish or whatever she's talking about——

Mrs. BURTON. I didn't ask that. I didn't ask you—first of all, its going to be an American system. It's the American Members of the House and the Senate that—and an American President that will have to sign the bill.

So that terminology really is not necessary.

I didn't ask which proposal, because we can spend all day here and maybe a year trying to talk about proposals.

I'm just asking you if you support the concept of a national health policy for all our people, the young, the old, and the in between. The young suffer a lot. Obviously, our senior citizens are suffering, we know that.

So all people are suffering.

Would you, as a medical doctor, be willing to state that you think we need a national health policy for our people? That's all I'm asking.

Dr. BARBACCIA. There is no question that I would agree and I'm sure that many members of the profession and other professionals would agree that we need a national health policy for all individuals.

Mrs. BURTON. As a man who is known for his interests in the things he talked about today, would you urge your colleagues to—I'm speaking of the medical profession—starting maybe from the San Francisco Medical Society, and then going up to the California, and then the AMA to try to resolve—help resolve this issue?

Because frankly, I think that if we had the American Medical Association on our side, I think we really would have a national health policy.

Dr. BARBACCIA. I think it's very fair and I think it's extremely important and i think that while I'm squirming a bit, I think that

there are very few of my colleagues who would not agree on a national health policy for all individuals that assure access, adequate payments, and services.

Now, you have been very correct in correcting me that we're not talking about a particular format, but at least a national health policy.

Mrs. BURTON. If you gave this conception some backing, and I ask you to go back to your colleagues again and give us this impetus, we would move closer to this goal. It isn't a question of desire. It's a need. I think that we might get together on policy, or policies, or how to implement a policy. We need your input—I'm not talking about you, personally, but we need the input of the American Medical Association; otherwise, we will never make it. It's as simple as that.

Dr. BARBACCIA. Well, let me just take the personal challenge to be sure that I take this back not only to our county society, the San Francisco Medical Society, but also to the long-term care committee of the CMA.

Thank you.

Mrs. BURTON. I thank you very much, Doctor.

Dr. Gee, I want to compliment you on On Lok. You know I visited On Lok, and I plan on visiting again.

It's true that you have a very fine health group and they do a lot of excellent work. However, your resources are limited, and the number of persons you can serve is also limited.

That is not enough.

I thank you very much and I want to see your material myself.

There is another panel coming. Could they come up front, please.

Are there any other questions, by the way, of the two people here? I apologize.

Mr. MELLO. Joyce.

[Pause.]

Mrs. BURTON. Will Ms. Sue Savage come up, and Ms. Cheryl Conrad, and Mr. Hall?

I want to tell you that I have to leave in about 10 or 12 minutes. So we'll have to wind this up.

So if you have long statements, if there is any way you can summarize I would appreciate that.

Mr. HALL. Yes, thank you, Congresswoman Burton.

We're here to discuss title XX which affects over 100,000 Californians, employing over 80,000 primarily older, minority women spending a half a billion dollars of Federal, State and local money in California.

It is a program that has been ripped with scandal or fraud and abuse, and we believe the committee should carefully examine the record that is being submitted for the purpose of investigating whether or not the suspicions that seem to be reasonable, as they were in three other cases in California, are indeed true.

We would ask that the testimony that we have, be submitted for the record, and that the two ladies with me be allowed to summarize their testimony.

Mrs. BURTON. Fine.

PANEL THREE, CONSISTING OF SUE SAVAGE, FORMER SUPERVISOR, REMEDY, SAN FRANCISCO; AND CHERYL CONRAD, SUPERVISOR, IN HOME SUPPORTIVE SERVICE PROGRAM, SAN FRANCISCO

STATEMENT OF SUE SAVAGE

Ms. SAVAGE. My name is Sue Savage.

I was employed as a field supervisor for a title XX-funded home-care agency in San Francisco.

More people are cared for by title XX under the in-home supportive services program than all other home-care programs of the Government combined.

In California, this amounts to over 120,000 members of our disabled, elderly, and poor population being served by over 80,000 workers costing the taxpayers close to one-half billion dollars.

California and the bay area have the distinction of being the locale for two very famous cases of fraud and abuse that have led to criminal convictions and jail sentences, specifically Peter Gottheimer and Flora Souza.

The taxpaying public has been repeatedly promised that the problems of contracting for these important human services would be corrected and made responsible.

It is my unfortunate obligation to inform you, Mr. Chairman, that this has not happened.

After thousands of clients were left unserved and homemakers unpaid by Peter Gottheimer's companies, some of the contracts were transferred to Flora Souza.

When she went out of business, the State did not reform the contract procedures and the result is that Remedy Home & Health Care has become the lowest bidder on many of the contracts served under title XX in California.

There are numerous documents concerning the practices of Remedy which I would like to submit for the record and for the review of this committee at this time.

Essentially, the records describe unfair employment practices in regards to the payment of wages and benefits to the homemakers working under title XX program.

Inadequate training of both homemakers and field supervisors providing services to the elderly, disabled, and blind population receiving in home supportive services. The poor quality of their services.

Recent documents concerning the award of the in home supportive service contract. History of the union's participation with IHSS contract in San Francisco.

Documents concerning previous IHSS contract awards and finally newspaper articles pertaining to past and present in home supportive service contract awards throughout California.

In closing, I would like to state my concern for the elderly population in San Francisco whom I have become acquainted with during my 4 years of working with the in-home supportive service contract.

This population is subject to often undetected abuses under the present contract awards system.

I've had the advantage of comparing the administration of two agencies providing services under title XX home supportive services program. I know how it should be done and I also know how wrongly it can be done. The award of these contracts cannot be determined just on the low-bidder basis. This is not a naval shipyard purchasing steel. We are dealing with the lives of thousands of frail elderly, disabled, and blind individuals. There must be some measure of quality of services being provided. Presently there is none.

I continue my work with the elderly and I'm committed to the improvement of these services. When this contract recently changed back to Remedy, I could not bring myself to administer the program by their philosophy of deceit and abuse. Therefore, I choose not to return to their employ. Once was enough.

I am fortunate to be in a position where I can venture out on my own, but what about the many other employees of this program who have no other choice. I implore you to investigate the inequities of this well intentioned and vitally needed program for the sake of both the employees and the clients.

Thank you.

Ms. BURTON. Thank you.

And you're Cheryl Conrad.

Ms. CONRAD. Right.

Ms. BURTON. You said you were a former supervisor. Of what?

Ms. CONRAD. I was a former supervisor of two home-health-care agencies.

STATEMENT OF CHERYL CONRAD

Ms. CONRAD. As you know, my name is Cheryl Conrad.

During the last 2½ years, I have had experience as a supervisor administering an in-home supportive-service program.

I have come to recognize during this time that the quality control of in-home-supportive services has been ineffective.

This has been especially evidenced during the 3½ months that Remedy Home & Health Care has managed the program here in San Francisco.

For example, the client-homemaker relationship which is of vital importance for quality care to be maintained has been abused by Remedy's practice of repeatedly switching homemakers from one client to another. Our clients receive the most intimate, personal services. They are bathed, they are groomed, they receive bowel and bladder care from their homemakers. They need these services in order to remain independent in their homes.

It can be embarrassing and demeaning for a person to psychologically accept that they need aid in these most basic of living skills.

However, if the provider is someone who has time and experience to build a trust relationship with that client, to learn which tasks are painful for the client to do which are possible for the client to do, and, more importantly, which tasks that client needs to be challenged to do themselves, then independence can be maintained in the home.

However, if the client is forced to waste important energy getting to know different homemakers, telling these homemakers where things are, what tasks need to be done in order to maintain their independence, if the client has to change their sleep patterns, and their eating patterns to accommodate homemaker change, then strength is lost. Psychological, emotional, and physical strength is lost.

This strength could be better used to maintain their health.

In the invitation for bids submitted to agencies who were bidding on this contract, it was stated that client preference should be followed as to who the provider is whenever possible.

This indicates that the State acknowledges that the client-homemaker relationship is of vital importance in the maintenance of good health.

Remedy has dismissed this directive. They have instituted a cost-saving policy of cutting nonbillable hours by cutting the time that the homemaker spends traveling from client to client. As part of this policy, homemakers have been taken off of cases that they have been on for years.

Information regarding the client care has been lost. Idiosyncracies as to clients' needs has been forgotten.

Our clients are often confused and forgetful people. They're often paranoid of strangers. Thus consistency in client care is vital for their emotional and psychological health.

I am speaking here of forced changes, not of voluntary changes.

It is difficult for our clients, due to confusion and extreme illness or not knowing the proper channels to go through to take the steps to retain the homemaker of their choice.

Due to this inability, our clients are being taken advantage of.

Second, the agency is paid for the number of service hours each client receives up to the maximum number of monthly hours authorized by the client's social worker. The more client hours served, the more money that is paid to the agency.

If a client goes into the hospital or leaves town on vacation, the agency doesn't get paid. Therefore, it is to the agency's advantage to make up hours wherever possible whether the client needs that time or not. That way the agency makes the maximum number of total hours and they get the maximum amount of money.

Under Remedy a client could have been on vacation during the first half of the month. During the second half of the month, they could have received twice the amount of normal service hours in order to make up those hours missed.

On the opposite side of the spectrum, when the maximum contractual level of hours is reached, the agency has no incentive to send in substitute care when homemakers are ill.

Clients who need service can be overlooked.

The emphasis is not based on the needs of the client. It is based on financial gain for the agency. There is no effective case management to encourage client independence. In fact the existing policies may encourage dependency.

My experience has been firsthand. I was employed with Remedy from the time they received the contract in August through this November when I was terminated.

I was not the only supervisor to have left. In the 3 plus months that they have had the contract, there has been a 20 percent change in supervisory staff due to differences with the company concerning decent and humane care for our clients.

I know that you might have reason to question my word as I'm speaking out against my former employer, but I hope that you will accept what I have to say as worthy of further investigation.

Today, following me was going to be another speaker, Kathy Swan, a woman receiving homemaker service from our agency. She entered the hospital this morning.

While I can in no way imply that she entered the hospital today due to poor care, I do know that the reason she was going to speak today was because she had cause to have issue with the care that she was receiving.

Our client population is oftentimes fragile.

Quality and effective care must be maintained for seniors and disabled persons or else our state will be spending millions of dollars more on hospitalization and long-term care and the independence of thousands of people will be cut short.

Ms. BURTON. Thank you very much.

Mr. Hall, do you have anything to add? Then I think that the panel here has a couple of questions.

I just want to ask you to summarize.

Mr. HALL. In summary, we're asking the committee to request a proper investigation of the charges that are contained in the testimony—the formal testimony submitted to the staff and to the committee for their review.

Ms. BURTON. And you agree with everything that was said here, I presume? Obviously, or you wouldn't be here.

Mr. HALL. I presume it to be true, and I have reason to believe that what was in the past is being repeated again.

Ms. BURTON. Thank you. I think Joyce Ream has a question.

Ms. REAM. It's not really a question. It's a comment and that is that, although this was a contract which came out of the Department of Social Services and not the Commission on Aging, in a sense this points up what I think is a common dilemma that we face, which is how to develop an integrated system of services locally which is satisfying to all of the seniors in a given community and how that relates to both a State and National policy.

I think as we start moving into arenas of performance based contracting, for example, with State area agencies on aging and the California Department of Aging, that some of the dilemmas that have occurred with the issues of contracting out of title XX services may also be ones that will be potentially faced by us.

I think it merits careful review on the part of both State and local authorities. We need to recognize that the ultimate beneficiary or the ultimate victim of our sources, or lack of them is the senior.

Ms. BURTON. Thank you.

Senator Mello, is there anything that you want to add to that?

I thank you very much on behalf of the chairman, Senator Pepper—we call him Senator because he was one. I thank you.

And on behalf of all of us here at the panel, I thank you very much.

And Mr. Hall, you and I are going to be in touch because you're carrying this burden and we'll work on it.

Thank you.

[The hearing was adjourned.]

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APPENDIX

HOWARD BILLINS,
Castro Valley, Calif.

CHAIRMAN: HOUSE SELECT COMMITTEE ON AGING,
House of Representatives,
Washington, D.C.

MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE: This is a letter to tell you in much detail, my experiences, frustrations, woes, and heart aches over a period of about twelve years being a full time caretaker and nurse of my wife who is a victim of Alzheimer's disease. It's been dreadful.

My wife, Mrs. Luril N. Billings, was a very successful, much adored and respected third grade teacher for many years. Her doctor once told me she was a very intelligent woman. I knew that already.

About thirteen years ago, however, she occasionally did or said something uncharacteristic or even dangerous. She came to a stop when driving at edge of a freeway as the sign indicated, but then started driving right out in front of a host of cars doing seventy to eighty miles per hour. I was barely able to stomp on the brake before three of us would have been killed in our car and Lord only knows how many other cars. Then she started to do it again. I was able again to halt the car, but took the driver's seat myself. Her comment then as it often was later was: "There's nothing the matter with me, what's the matter with you?" She was very angry that I drove the rest of the way.

There were several other incidents later that nearly resulted in auto accidents.

Her memory for recent events or conversations failed at times, but seldom enough that I really realized anything serious was wrong. She was her good old sharp self 99% of the time.

Very slowly, though, these failures increased. She would come home from school and say, "My kids got a good laugh at me today and told me I had started the same lesson with them today for the third day in a row. Then she would laugh it off. I started pressuring her to retire. She had five years left and wanted to continue. It was some hassle to get her to agree. I had to take all the action and fill out the papers, etc. to get the retirement accomplished. These things I mention because there was now coming much pressure and perplexity on me. There is a gray zone between normality and bizarre behavior. Sometimes, I thought she was just trying to be ornery, which was not like her at all.

On a trip through Europe taken right after her retirement, she became so tense, angry over nothing, and unreasonable that I twice considered leaving the tour and trying to fly her back to USA to get help. I very seriously wondered if I could manage to get that done. Fortunately she then got alright till we got home. Dear reader, this was pressure and travail. You cannot understand it unless it has happened to you.

On arriving home again, I promoted with her each of us having a multi-phasic medical examination at Kaiser Permanente. She agreed. When we went to get the results, from which I wanted to get expert help for her, I tried to whisper to her doctor that it was urgent to have a private conversation about her. The doctor then said: "It is not my policy to ever talk to one member of a family behind another family member's back. Mrs. Billings, your husband seems to think there is something wrong with you. Do you think there is something wrong with you? I mean do you think there is something wrong with you mentally? I think you are alright and I don't understand your husband at all."

Since she had now managed to crush the feelings of my wife and me also, I had to make a scene. One cannot get directly to a Neurologist at Kaiser, but must be referred by another Physician. So I said, by God, I wanted some help from someone who knew something. The dear doctor said: "Well, if you insist, I will refer Mrs. Billings to Dr. Bernstein in Neurology." I said I insist and then some. I included this

story here to illustrate the fact that we meet up with many hurting, frustrating and dreadful events from time to time. I could list dozens.

Next problem, how to get a lady who knows she is alright to go to the Neurologist. It was accomplished finally after a hassle by saying, "You know your memory is not working 100 percent. This doctor is a specialist at helping people with their memories."

Dr. Bernstein left my wife in the waiting room, took me into his office, and let me talk to him a very long time during which I described her behavior. Then he took me to the waiting room, took my wife into his office and gave her some simple mental tests. She laughed about them later. Said she just could not remember simple things. Dr. called me back into his office and said it appears to be Alzheimer's. I had never heard the word before. Couldn't spell it.

Next day I got to a library, got two books on mental diseases, read in one of them a good long excellent account of this—and have never seen anything since that tells it as clearly and well. Now I knew the hell we were both in for. I am a male, put in four years in the army in World War II, but I'm not ashamed to say, I went to my room and wept.

So far as I knew, we were completely alone in the world with this terrrible prospect of years of sinking into the abyss. I was somehow ashamed of the situation and did not want anyone to know. I tried to imagine what the future would be like and how in God's world we'd ever cope with it.

I decided I would never tell my love that she had a terrible, hopeless, brain destroying disease called Alzheimer's. I would protect her, comfort her, fend for her, stay with her, pet her, love her, sing with her, some day care for her like one must for a newborn babe so long as God would give me the sense and the strength to do it. 12 years later God gives the sense and the strength to do it. About forty-eight years ago we fell in love and pledged ourselves to each other "forever and six years." The marriage ceremony had something in there "for better or for worse" "in sickness and in health." I've never used the word Alzheimer's nor described it around my wife when she still had enough awareness to be hurt. I'm sorry for people who can't understand the above.

But she knew something was tragically wrong. In the gray stage. We found a piece of paper on which she had written, "something is going wrong in my head." Twice she wept bitterly. Only times I ever knew her to weep.

The last thing she has been able to remember is the Lord's prayer. Catholics call it the "Our Father." She asked me to always say it at bedtime. I do and I can tell she knows that much, for sometimes, after each phrase, she can grunt "uh huh".

This lady cannot walk, cannot talk, cannot recognize anyone, cannot control her bowels or urine or realize when these functions happen, cannot eat except to be spoon fed, cannot tell you where she hurts or whether she hurts, cannot tell she is in her own home, and cannot write a letter to Congress to tell them her husband caretaker is getting pretty desperate about the future of her care and his, too, for he is 68 years old and beset by a multitude of problems.

Just a couple of weeks ago I finally got to the dentist to have my teeth cleaned. He scolded me for not having been there for six years. Said he, "How can I care for your teeth and gums if you never come here?" During those six years I have been tied down in a state of virtual house arrest twenty-four hours per day, every day for weeks, months and years. Those 24 hour days have aptly been called thirty-six hour days in a book on care of Alzheimer's victims. The Caretaker Is in Jail.

True to human nature, most relatives and friends, congratulate and praise you for doing a great job, and then leave you and forget you. Some don't even look at the victim if they happen to come into your home.

Every day of my life, I scrub, cook, wash dishes, polish, shine, make beds, sweep, do mountains of laundry, clean bathrooms, carry out garbage, keep books on family income and outgo, maintain yard and garage, care for dogs which were once great company and therapy for wife and so on; total maintenance person.

In addition: I am the complete nurse, I bathe her, I doctor her skin, I wash her hair, I brush her teeth, clip finger nails and toenails, I dress and undress her, I spoon feed her, I clean up her urine over and over and over again, I clean up her defecations and clean her bottom, I stay very close to her to observe effects of medicine, and I see that she has eight glasses of fluid per day.

I have to lift her several times per day. She is about 150 pounds of dead weight. I weigh 145. My back is getting to a stage where it just cannot take it. What happens if I go under? Why does not Medicare recognize Alzheimer's as a disease? The doctors say it is a neurological disease.

I'm worried, I'm scared, I'm distressed, have been for years and years, and I am very, very, very, very, tired.

During the Civil War Lincoln once said he was tired, a kind of "tired" that sleep could not cure.

We who are nurse-caretakers of victims of Alzheimer's have that Lincoln kind of "tired."

Please help us.

HOWARD BILLINGS.

P.S.—And every night I have bad dreams.

WRITTEN TESTIMONY SUBMITTED BY KATHY CAPOBIANCO, UNITED DOMESTIC WORKERS OF AMERICA'S COLLECTIVE BARGAINING DIRECTOR, ON THE IHSS PROGRAM

The United Domestic Workers of America appreciates this opportunity to present written testimony before the Senate Subcommittee on Health & Long Term Care on the In Home Supportive Services program, one of the six remaining Title XX programs mandated by AB 2X.

First, a brief word about the UDWA. We have been in existence for about four years and have approximately 4,500 members around the state. Our members are all employed as homemakers, the service providers, in the IHSS program in 9 of the 17 California counties which have opted for the contract mode of service delivery. As representatives of those who actually do the work of the program and who therefore have the most regular contact with recipients, we believe we have a unique and valuable perspective on the relative effectiveness of modes of delivery as they affect the quality of the program for both workers and the clients. We have also worked very hard on the legislative aspect of the program as members of the In Home Care Council, an industry-wide council composed of both labor and management, and were successful in passing AB2712 (Floyd) in the last legislative session, which permits contracting for two years with an option to renew for a third, and also sets up a pilot project to demonstrate the effectiveness of various modes of service delivery. We also spent a great deal of effort to secure the passage of AB 2X to ensure the return of a little of the money to the IHSS program which has been lost through federal cuts and SB 633.

We are very much aware of proposed further federal reductions and the overall shrinking of the "pot" for social services. While we believe it is shortsighted and in the long run more expensive for the federal government to reduce allotments to the very programs that could save money in other areas (long-term care, for example), we recognize the unfortunate political and fiscal realities of the present time. Our testimony today focuses on the failure and inability of the IHSS program as presently organized to meet the stated national goals of Title XX and especially the consequences of poor program monitoring and evaluation.

The success of the IHSS program should be measured by the quality of service delivered. High quality service is only possible if the workforce is trained, supervised, regularly evaluated and receives the living wages and basic benefits to which all Americans have a right, such as health coverage, work related travel reimbursements, paid holidays and minimum vacation benefits etc.

We believe it is possible to include all these critical ingredients in the IHSS program design when the State and Counties correct the administrative waste and program deficiencies perpertrated by the Individual Provider (IP) mode of service delivery, the dominant system utilized throughout California. This system is seriously deficient in administrative monitoring of finances and the supervision of work so that precious funds are wasted in the delivery of less than optimum quality service.

The IP system, in theory, operates through recipient-recruited, trained and supervised workers paid for by the State payrolling system. In practice, the State pays for unscreened, untrained workers recruited and hired unseen by County social workers forced to act as reluctant employment counselors who solicit homemakers who are then under paid in a system which tolerates padding of service hours, payment for hours not worked and permits conditions under which the lack of decent supervision results in the abuse of clients by workers and workers by clients. The lack of monitoring of the IP system results in little accountability for taxpayer money spent to ensure the health and safety and relative independence of the frail elderly and disabled. This is all especially galling when better alternatives to the IP system exist and have a demonstrated history of success. Where ever counties have contracted for services, either through private companies, non-profit agencies or to the County itself, there is a much higher quality and cost-effective program evidenced in part by dramatic reduction of complaint rates.

In addition to built-in systems of accountability which maximize taxpayer expenditures, under contracting there is usually close supervision of trained workers delivering higher quality service than provided under the IP system.

To summarize, the IHSS program will only begin to meet Title XX goals and work effectively until the IP system is drastically overhauled and replaced by an improved contract system of homemaker service delivery which does not rely solely on the rigid bottom line of low bid contract awards. We want to relate our observations and suggestions for improvement.

The appropriate role of local governments: We believe the appropriate role for counties is to make sure that the program is administered in an acountable and responsible manner. This requires monitoring the supervision of the workforce—two elements not possible under the IP system, but fundamental to contracted programs.

Direct provider administrative costs: Under the IP system the County incures a number of hidden costs that do not appear in any financial accounting of the program. (1) for example, because the frail elderly are often incapable of securing their own homemakers, under IP it is social workers who end up functioning as employment counselors, positions for which they are neither trained or paid, and which take away enormous amounts of time from their regular social work responsibilities. (2) As a matter of interest, supervisory personnel who recruit and train under contracting modes are paid much less than social workers. (3) Another "hidden" cost under the IP provider system is the cost of County of medicare and other benefits which underpaid workers must receive in order to survive-private health insurance coverage, for example, when obtained for contract workers costs considerably less over the long term and provides better quality care.

Impact on recipients by the program changes and funding reductions: As you are probably aware, the impact on recipients of program changes through SB633 and through funding cuts have been devastating. The distinction between "comfort" and "safety" made by the bill is not always easy to make in specific cases involving frail elderly clients for whom the so-called "comfort" of more regular cleaning, cooking, bathing, shopping, etc., can make the difference between maintaining a basic health level to a deteriorating condition leading to institutionalization (and at a much greater cost to the state). The very real question this problem faces when costs are considered is, when is a little help worse than none? For example, in some situations shopping for clients has been reduced from weekly to monthly. Not only do these people not have refrigerators large enough to accomodate a month's worth of groceries, but their diets need quantities of fresh vegetables and fruits which are impossible to keep for a month. Another example: A weekly insteady of bi-weekly bath can result in bedsores; a clean body returned to a bed with dirty linen (because the laundry chore has been cut out) has obviously little use. A much more careful individualized approach is needed than the arbitrary assignment of minutes per task set up to cope with the requirements of the bill, which, parenthetically, we supported for its efforts to reduce waste.

Mechanisms to involve recipients and constituents groups in setting priorties: We heartily applaud this suggestion and proposed that a most important constituent group to involve is workers or their representatives. The mechanism might be to mandate what already exists in some countries: a Homemaker Service Review Committee made up of County representatives, representatives of clients and of workers who meet on a regular monthly basis and report to the Board of Supervisors.

Setting priorities to maximize utilization of few dollars: A basic priority should be to cut out existing waste of those dollars through the elimination of IP system. A contract form of delivery would make the most use of the available dollars through monitoring and supervised reporting practices required in a bid or proposal.

Develop monitoring and evaluation mechanisms: Effective monitoring and evaluation can only occur through some form of contract. A minor example is that under a contract, the contracting agency can be fined ($50 in San Diego, for example) if a worker does not show up to an assignment; under the IP system the chances of such a non-show being reported are minimal. Our office has more than once received calls from distraught and frightened clients who have not seen or heard from the independent provider and were unable to contact an assigned social worker.

Achieving or maintaining self-sufficiency * * * The IP system which revolves around mutual dependency of a client for service on one worker, in turn dependent on one client for wages encourages dependence. In contrast, a contract mode of delivery by guaranteeing service hours for the worker ensures employment and motivates the worker to encourage and to teach her client to become more independent and self-sufficient. Trained workers, as required by a contractor are also in a better position to teach independence than untrained individual providers.

Preventing or remedying neglect, abuse or exploitation * * * Again, the IP system actually encourages such abuse because there is no accountability, no motivation for the worker to receive training, and no incentive for the worker to be accountable except for good will. Even recruitment is risky since there is no screening and there are no standards—there is nothing to prevent an abusive worker from being hired. And conversely, a worker with grievances has no authority to which an appeal can be directed.

Preventing or reducing institutional care * * * This goal is impossible from the outset when no provision is made for caseload growth. Since more citizens will qualify for IHSS regardless of money provided or not, the consequences are an inevitable decline in standards of care because of the increasing numbers which must be provided for with the same amount of funding. A further related issue is that of those people already in institutions who do not need the amount of care provided and who would be more cost-effectively and happily served in their own homes (Congresswoman Millicent Fenwick estimates 20 to 40% of the population of institutions come under this category), but because of funding limits will not be able to take advantage of the program.

In short, the current system is crisis oriented with only time and money to deal with the most serious cases and little or no room for prevention.

In conclusion, we believe that IHSS does not belong under Title XX at all. We support efforts on a federal level to set up Title XXI, a separate entitlement program dedicated to preventive community oriented health care. We also believe there is an increasing necessity for In Home Supportive Services as an alternative to the institutionalization of the frail elderly and disabled of our community. We hope you will take an enlightened attitude toward the homemakers who are the key to the ultimate success of any high quality program and progressive approach to ending the feudal IP system. Home health care is not only more humane and dignified, but it is almost always provided at a considerably lower cost to the taxpayers.

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD BY CARROLL ESTES, PH.D.

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FISCAL CRISIS: THE STATE OF STATES

I am delighted to share with you my views about the state of the states. Although the views that I am expressing are strictly my own, they are based on more than a decade of research on issues of concern to us today.

Immense changes in public policy, the economy and in ideology are affecting the states and the roles they must play in services for the elderly.

FISCAL CRISIS

One of the most dramatic impacts to hit the states has been the fiscal crisis. A fiscal crisis at the federal level was formally declared in 1981 by the President, by other politicians and by a number of economists. This declaration was preceded by statements—some dating to the early 1970s that viewed the federal role in domestic social programs with alarm. The declarations of fiscal crisis first began to be reflected in public policies at the state and local level in the late 1970s, along with California's Proposition 13 in 1978. The media and the public came to accept this crisis definition of reality.

I think it is important to state that "crises" that come to national attention do not do so solely, or even largely, because of "objective", factually demonstrable (and essentially non-political) conditions. Such crises may be socially produced (or constructed) as a consequence of social perception and the definitions of influential politicians, the media and others, who in turn, are swayed by politics and economics. My assertion that fiscal crisis may be socially produced or constructed is not meant to deny the existence of objective phenomena such as inflation, recession, lowered productivity, or other conditions that may be said to be empirically real and that affect the economy, regardless of how they are perceived.

Social action, however, is indivisible from the socially constructed and accepted ideas that define and interpret these phenomena. The declaration by politicians, for example, that there is a fiscal crisis may in itself create a favorable environment for state actions to reduce taxes which (if passed into state law) significantly reduce

state revenues—creating the empirical phenomenon of revenues lower than expenditures—our definition of fiscal crisis.

The declarations of fiscal crisis in the 1980's at the national level has had much the same effect as it had at the state and local levels beginning in the 1970's—tax reductions and cutbacks.

The declaration of fiscal crisis at the federal level has created a second fiscal crisis for the states. In 1978, states (taken as a group) spent a higher percentage of their budgets on health care than did the federal government, even while absolute federal expenditures for health grew to more than double state and local health expenditures combined (Clarke, 1981). More specifically, Medicaid currently accounts for about one-third of state and local government health care expenditures and often it is the largest program in a state's budget (Freeland and Schendler, 1981). This must be taken into account when we speak of both the strain on state budgets and their consequent response to that strain. In examining determinants of state policies, our research shows that fiscal crisis has been a major factor. The data from the states show a direct correlation between the level of the fiscal crises in state budgets and the number of policy reductions made by states. Those states with greater crises made more policy changes to lower costs and were more likely to lower the rate of growth in their Medicaid budget.

It is within this context of a declared fiscal crisis and the increasing blame placed on people rather than policies that I approach the subject assigned to me: The States of the States: This subject has been chosen for special attention because the Reagan Administration has repeatedly said that the Federal government has grown too large and that states should now take on more responsibility but with reduced federal resources.

This idea is not new. The Advisory Commission on Intergovernmental Relations has documented proposals since the 1950s to pare down the Federal government and build up the states. At one point, Lyndon Johnson apparently gave serious consideration to Walter Heller's proposal to introduce a revenue-sharing component into the total array of federal assistance to other units of government. Richard Nixon had his version of the New Federalism and he established a few block grants and helped establish a mindset for decentralization. Jimmy Carter also frowned upon big government in Washington. But President Reagan's New Federalism is more than a mere tinkering with the placement of programs; it is combined with economic, fiscal, and philosophical doctrines that provide powerful impetus for change.

Embedded in the austerety politics of the 1980's have been the President's efforts to shift responsibility from the federal to the state and local levels, and wherever possible to the individual and the private sector. Perhaps most important, New Federalism proposals have been re-introduced in the crisis context, with arguments that the costs of federal social intervention is, in itself, harmful to a productive economy and that the individual and family must increasingly bear the responsibility for illness, poverty and unemployment.

Considerations of state capacity to assume responsibility must acknowledge the fiscal context within which state and local governments are operating, the interrelationship between state and federal economic conditions and policies, and the real (and growing) revenue disparities across different states and geographic regions (U.S. House, 1981a). Significantly, as Governor Matheson of Utah has stated, states are not in control of the key economic policies that vitally affect poverty and the levels of unemployment (and thus benefit demands) in the state. Further, resources are unequally distributed across the states. Some have argued that a hands-off federal aid policy is irresponsible, given that the states and the welfare of state residents may be drastically affected by changes in industrial and manufacturing bases, in gas and oil prices and demand, and in federal policies associated with them or with other aspects of the economy.

Two fundamental questions concern the state of the states in the context of fiscal crisis and New Federalism: *First*, do state and local governments have the fiscal capacity to deal effectively with their programs in welfare, education, transportation, social services, and health? *Second*, how will the increase in state responsibility and decrease in uniform federal policy affect access to health care, especially under conditions of austerity?

FISCAL CRISIS RESEARCH

Our research at the University of California, San Francisco and the studies of others show that in the late 1970s, many states began to experience fiscal problems, at least some of which followed the political declaration of crisis and subsequent laws to limit or reduce taxes (e.g., California's Proposition 13). More than one-third

of the 230 policy-makers and state and local officials who we interviewed in ten states and thirty-two localities reported a fiscal crisis within their state or locality between 1978 and 1981—that is, prior to the major federal budget reductions and policy changes that began in 1981 (Swan et al, 1982). An equal proportion reported their state and local government's fiscal outlook as "poor" to "very poor." As early as the fall of 1981, less than one-third reported their government's fiscal outlook as "good." For the 1980–81 period, more than half of the official city (55 percent) and state (53 percent) budget administrators reported a budgetary shortfall in revenues at their respective governmental levels. This may explain our finding that many states and localities had already begun to cut programs and services before the federal cuts in the Omnibus Budget Reconciliation Act of 1981 (Table No. 1) and before the impact of the recession of 1981–82 began to be felt.

Among the human services cut in the 1978 to 1981 period, social services were hurt the worst at both the state and local levels, but these were closely followed by cuts in health services. Approximately 60 percent of the 32 cities we studied reported cuts in social and health services for this period. When we asked service providers in the localities to tell us about their projected budgets for 1982, the result was fairly dramatic (Table No. 2). Cuts were expected from all levels of governmental support, and more heavily in social than in health services. Fully 94 percent of social service providers in the communities studied projected cuts from the federal level, as did 68 percent of health service providers. Community service cuts also were projected from funding sources derived from the state and local levels in both cases again more severely for social than health services. The projections proved to be very accurate.

In eight (8) of the ten states we studied in depth, public officials reported their government's revenues had (or would) fall short of what was required to maintain existing levels of expenditures both in 1981 and 1982. (See Table No. 3.) The percent of localities studied that projected shortfalls increased from 91 percent (29) to 97 percent (31) between 1981 and 1982. Not surprisingly, over 80 percent of all public state and local officials interviewed reported expenditure reductions as their major response to these conditions in 1982—although a sizable number of local and a smaller, but increasing percent of state officials noted revenue increases as another strategy used to meet their budget deficits.

Of the state-level officials who reported budgetary shortfalls, more than half (6 out of 10 states studied) reported human service cuts as among the "most important" things they did to reduce expenditures both in 1981 and in 1982 (Table No. 3). About half of the states reported that across-the-board cuts had been invoked. Further cuts followed, as we know, in 1983.

In contrast, the major local-level responses to shortfall for both years were in reducing the cost of public employees through staff reductions, increased workloads, and hiring freezes—which we found correlated with local level health and social service cutbacks reported by providers. In other words, cuts in public personnel also resulted in cuts in health and social services.

Our findings of pre-1981 declared crisis, actual shortfalls (with expenditures exceeding revenues) and cutbacks are understandable in the context of 50 state data. Almost two-thirds (64 percent or 32 states) of the fifty states had enacted income or sales tax reductions before 1980 (between 1977 and 1980). Another 38 percent (19) of the states had enacted spending or taxing limits prior to 1980 (between 1975 and 1980), and 14 states had both kinds of taxing and spending initiatives imposed on them. In California, the combined impact of the Proposition 13 and other tax cuts, plus the recession was to reduce revenues in 1983 to at least $14 billion below what they would have been (annually) without the cuts. California has moved from a $7 billion surplus to a $1.4 billion deficit. California's budgetary tax, education, health and welfare policy problems are more serious in 1983, than at the depth of the recession in 1982. Indeed, California continues to face its worst fiscal year crisis since the Depression of the 1930's.

But California is not alone. Our analysis (Table #4) of the number of states experiencing a falling budget balance demonstrates a complete reversal in the number of states reporting a surplus in 1978 (when approximately two-thirds of the 50 states reported a surplus of 5 percent or more), compared to 1983 (when less than one-third of the states show such a surplus), and the number of states projecting a deficit has grown (Swan, Estes and Wood, 1983).

A recent 50 state survey from the National Governors' Association showed that most state budget balances would be at an all time low at the end of June, 1983, when the net national balance of all 50 state budgets would total only $345 million, compared with more than $11 billion just three years ago. As this report noted: "Because state deficits are illegal, a surplus of at least five percent is built into most

state budgets to allow for unexpected expenses or loss of revenue, such as most states suffer in recessions. But 26 states will end with balances under one percent this year and 29 will fall below one percent next year" (S.F. Chronicle, 5/24/83).

Now, I would like to speak more specifically about state budgets and their responses to the growth in Medicaid expenditures.

MEDICAID 1982–83

Our own studies of Medicaid, focused on the 1982–1983 period, show that the federal budget cuts and policy changes in 1981 and 1982 both encouraged and gave states greater latitude to make policy changes. Most of the state Medicaid policy changes in 1982 were cost containment strategies aimed at reducing the growth rate in program spending since most states are experiencing problems with program deficits in their Medicaid programs. However, it should be noted that the expenditure increases creating these deficits have not primarily resulted from population increases or eligibility or benefit expansion, but instead from increases in provider prices and charges. For example, nationally the number of aged Medicaid recipients has declined by 14.3 percent since 1976 (5 percent of that since 1980 and 1981).

Our research findings for the 50 states show that:

(1) In 1982, states abruptly stopped increasing their benefit policies, although benefits were added in instances where they thought to be tradeoffs for more costly institutional services.

(2) In 1982, almost all states made reductions in the number eligible for AFDC Medicaid. Approximately half of the states made other minor changes to reduce the number of eligibles, particularly in the medically needy programs. These are poor people who will either go without medical care or will require some form of state or local government aid if they require hospital care.

(3) These attempts to control the number of eligibles, however, were not successful because of the offsetting effects of the increase in numbers eligible due to high unemployment.

(4) Almost all states have failed to make adjustments in their state supplemental payment programs to keep pace with inflation between 1978 and 1982, directly reducing the number of Supplemental Security Income (SSI) individuals eligible for the Medicaid program. This policy has had the single most dramatic effect on reduction of those eligible for Medicaid.

(5) States have begun to adopt alternatives to the Medicare reimbursement policies for their hospital Medicaid programs. Twenty-two of the fifty states have adopted more stringent hospital Medicaid reimbursement policies, and many others are considering such changes. Utah has adopted a prospectively determined rate-based on severity of illness and case mix, using DRGs. Medicare will follow suit in Utah next July.

(6) The benefit expansion in community based services as a substitute for institutional services has been generally limited to demonstration projects or to limited groups or limited geographical areas. Therefore, the increase in community based alternatives (e.g., long term care for the elderly) benefits is not expected to be significant or measureable in terms of either state utilization or expenditures per recipient.

HEALTH CARE UNDER NEW FEDERALISM

As a consequence of public policy trends established in the mid-1960's and the 1970's. The planning and administration of state level health service programs has generally been based on the assumption of continued growth, or at least of maintenance of effort. Although many programs have been state-administered, basic funding and other policy decisions have been made at the federal level. Moreover, present health programs have evolved over a period of years, largely but not exclusively, in reaction to initiatives from the federal level. Many of these assumptions are now being seriously challenged: program growth has largely stopped, and in many cases programs are shrinking; greater administrative and programmatic responsibility is being given to states through block grants with reduced funding. Further, these major changes have been introduced over a very short period of time and the future portends still more changes. Thus states, are faced with the increased fiscal and program responsibilities, not only in one program area but in the multiple areas—and at a time both when many programs are undergoing federal cutbacks and when state administrative resources are dwindling, due to intensified state and local fiscal problems.

Furthermore, a number of federal spending reductions are coming via the block grant approach, with another 12 percent budget reduction proposed for fiscal year 1984—this on top of 20 to 25 percent reductions imposed in the 1981 cuts.

In our current research, a 1983 survey of state health departments in eight large states (from 8 federal regions) reported the effects of the combined reduction of both federal and state funds. The effects are apparent in both personnel and services. Five of the eight sample states reported laying off and reducing personnel. These losses, as high as 2,000 employees in one state, were tied directly to loss of federal funds and restricted state funds. Although none of the states had eliminated services, 4 of the 8 state sample health departments reported initiating fees or co-payments reducing in the volume of services, and tightening of eligibility.

Relative to state policy changes or cutbacks and their effects on the state health departments—California initiated the Medi-Cal Reform Act re-defining what was a "medical necessity"; Washington increased fees in the areas that had not had fees before; Missouri eliminated hospital subsidy for care of indigents so that they can no longer respond to emergency public health problems—just to cite a few examples.

Let me close with a comment about New Federalism, fiscal crisis, and the decentralization of national health policy as it relates to the academic health center.

We are all familiar with the impact of such national health care policies for the support of biomedical research, health care for the elderly (Medicare), and hospital construction (Hill-Burton).

Under policies of New Federalism and decentralization I see five major issues:

(1) National policy goals (e.g., access to health care for the poor) are supplanted by the more autonomous and variable state (and in some cases, local) policy choices, particularly with regard to programs for the poor of all ages. This means that there will be even less consistency or uniformity of health policy for the disadvantaged across different states;

(2) With block grants and reduced federal control, the capacity of all but the most powerful constituencies is weakened—because, to assure a uniform basic level of human services, a constituency will need the resources and capacity to influence 50 state governments and possibly thousands of local governments (the poor usually do not have such organizational strength). The academic health centers, particularly the medical schools and teaching hospitals, have focused on Washington and federal policy—not state policies. But increasingly, health manpower policy and third-party reimbursement policies will be decentralized.

(3) The more health programs are consolidated into a small number of block grants, the less likely there will be a solid constituency behind these grants, and the easier it will be for legislators to make further cuts in them in the future.

(4) Decentralization in austerity places human service demands on the most fiscally vulnerable levels of decision making, where state and local governments are subject to immense fiscal pressures and revenue shortfalls.(1) Decisions about health services for the poor are thus located precisely where pressures to control social expenses are greatest—(and where the need to maintain the state and local economy forces these governments not only to limit corporate taxes but also to provide additional economic incentives to business) "Friedland, Alford and Piven," 1977; David and Kantor, 1981); and

(5) The policies that most benefit the upper and middle income groups tend to be "national" policies (e.g., Social Security, Medicare, military spending and tax subsidies). These truly national policies (although also under fire) are more easily protected, uniform, and visible. Policies for the poor (such as Medicaid) tend to be state-level policies, which are not only highly variable and inequitable from state to state, but also increasingly vulnerable to cutbacks with the federal policy shifts and the extreme fiscal pressures on state and local government (Estes, 1982; Nelson, 1982; 1983). It is the poor, aged and young people who are most heavily dependent on state-determined benefits of Medicaid, block-granted social services, and SSI supplementation, who are particularly vulnerable to these cutbacks in state policies during this austerity period.

These are not easy issues. I look forward to hearing how the state of Utah and the University of Utah are dealing with them.

Thank you.

TABLE 1.—STATE AND LOCAL CUTBACKS IN SERVICES: 1978–81

	Number reporting cutbacks by Government at level	State No. (N=10) percent	Local No.	(N=32) percent
Cutback area: Services/benefits:				
Aging services	1	10	14	44
Health services	4	40	19	59
Social services	5	50	20	63
Income maintenance	3	30	8	25

Item asked: "Since 1978, has (State/Local) government spending in the following areas been: greatly cutback, cutback, left as same level, increased, or greatly increased?"

Source: AHPC Fiscal Crisis Elite Survey, Public Influential Instrument

TABLE 2.—PERCENTAGE OF PROVIDER RESPONDENTS ANTICIPATING EFFECTS ON OWN AGENCY OF 1981–82 GOVERNMENT EXPENDITURE CUTS: URBAN LOCAL LEVEL

[In percent]

	Providers		
	Health	Social services	Total
Cutback source:			
Federal	68	94	72
State	60	71	61
Local	35	62	39
Total (N)	(90)	(16)	(106)

Item asked: "Are you anticipating decreases in Federal, State, or Local funds in the coming year that will affect your budget?"

Source: Fiscal Crisis Elite Survey, Health and Social Service Providers Instruments.

TABLE 3.—STATE AND LOCALITIES REPORTING BUDGETARY SHORTFALLS AND GOVERNMENTAL RESPONSE

	State (N=10)				Local (N=32)			
	1981		1982		1981		1982	
	No.	Percent	No.	Percent	No.	Percent	No.	Percent
Fiscal shortfall exists [1]	8	80	8	80	29	91	31	97
Important Governmental responses reported by those indicating shortfall: [2]								
Expenditure reductions	8	80	8	80	28	88	28	88
Revenue increases	3	30	5	50	16	50	17	53
Human service cuts	6	60	6	60	10	31	10	31
Across the board cuts	4	40	5	50	15	47	17	53
Cuts in public employment costs	7	70	5	50	26	81	25	78

[1] Represents the number of States/localities with at least one public influential respondent reporting a shortfall in the period indicated.
[2] Represents the number of States/localities with at least one public influential respondent reporting the indicated response to fiscal shortfall. The number of States/localities with shortfall indicated represent the maximum number of possible for a given response.

Source: AHPC Fiscal Crisis Elite Survey, Public Influential Instrument.

TABLE 4.—STATE SURPLUS (BUDGET CONDITION): 1978 AND 1983

	Number of States, by year			
	1978		1983	
	No.	Percent	No.	Percent
Condition of State surplus:				
0 to 5 percent	[1] 19	38	[2] 35	70

TABLE 4.—STATE SURPLUS (BUDGET CONDITION): 1978 AND 1983—Continued

	Number of States, by year			
	1978		1983	
	No.	Percent	No.	Percent
More than 5 percent	31	62	15	30
Total	50	100	50	100

[1] One State had a negative (deficit) balance in 1978.
[2] Two States had a negative (deficit) balance in 1983.

Source: National Governors' Association, and National Association of State Budget Officers. Fiscal Survey of the States: 1978–79, Table A–2; 1979–80, Table A–2; 1980–81, Table A–3; 1981–82, Table A–2. Washington, DC: NGA and NASBO, 1979; 1980; 1981; 1982. Bureau of the Census. Statistical Abstract of the United States: 1979, Table 493; 1981, Tables 1175, 1307, 1416. Washington, DC: U.S. Department of Commerce, 1979.

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STATEMENT OF WILLIAM LAURENCE GEE, PRESIDENT, ON LOK SENIOR HEALTH SERVICES, SAN FRANCISCO, CALIF.

THE NEED FOR A NATIONAL POLICY ON LONG-TERM CARE

My name is William Laurence Gee. I am a practicing dentist in San Francisco's Chinatown. I am also now a member of the San Francisco Commission on the Aging; Chairman of San Francisco's Adult Day Health Planning Council; and the

Vice Chairman of the United Way of the San Francisco Bay Area. But, it is in my capacity as President of On Lok Senior Health Services that I am speaking to you.

On Lok is a nonprofit community-based organization established in the early 70's to serve the needs of the sick and impaired elderly of San Francisco's Chinatown/North Beach area. Over the last 12 years, On Lok has had the privilege, through research projects, demonstrations and waivers, to develop and refine a long-term care system which helps the older impaired peraon remain in the community. In 1972, On Lok developed a day care center, using the only space available—a converted nightclub. By the end of 1974, that day center was California's first Medicaid waiver demonstration of what now is a statewide Adult Day Health Service program. With model project funding from the Administration of Aging, On Lok expanded its community service system from 1975 through 1978, building upon day health and including in-home services, social day care and housing. In 1979 On Lok began a new demonstration now known as the Community Care Organization for Dependent Adults—or CCODA. With Medicare waivers from the Health Care Financing Administration and research and development funds from the Office of Human Development Services and the Administration on Aging, On Lok developed a comprehensive long-term care service system. On Lok's CCODA was built on the management and financing principles of the Health Maintenance Organization (HMO).

So, for the past four-and-a-half years, On Lok has provided all health and health-related services—from transportation to hospitalization—to older people so frail they are certified by the State of California as eligible for placement in a skilled nursing facility. Medicare reimbursed On Lok for all its service delivery costs and On Lok's professional multi-disciplinary staff had the freedom and flexibility to provide the services needed without regard to normal reimbursement requirements, restrictions or constraints.

Our expectations for On Lok were realized and even surpassed. First, On Lok found that indeed many people can be kept out of nursing homes. While all of On Lok's participants have been approved for nursing home placement, today less than three percent actually reside in a skilled nursing facility. This is less than the national average for the *total* population over 65 years of age. Second, and more important from the Medicare perspective, hospital days have been reduced. Since 1979, On Lok has been able to reduce its percentage of hospital days from over two percent to now just over one percent of total days. This rate is comparable, again, to hospital use by the *general* Medicare population—both healthy and frail. Third, community services were considerably increased. Nearly all of On Lok's participants attended a day health center at least a few times a month and some attended daily. Many received in-home services. Fourth—the bottom lines—costs were favorable.

Although community service costs were high, savings from acute hospitalization and skilled nursing offset these. On Lok's total per capita cost—now $1,220 per month—is only about 85 percent of what Medicare and Medicaid usually pay for such frail persons.

There are a number of points I would like to make based upon On Lok's experiences.

Above all, long-term care can be and should be an integral part of a community's health delivery system, It should be community based and that means two things. First, persons should be able to receive services while remaining in their own home and in their own community. On Lok's philosophy, from the very beginning, has been to help the older person remain at home as long as it is medically, socially and economically feasible. On Lok has found that while some people need hospital and skilled nursing care at some times, overall much of the skilled nursing placement and some of the hospital placement can be reduced. Second, community-based means community controlled. The long-term care system needs to reflect and be scrutinized by the community. On Lok's doors, for example, are always open. Family members and others come in and become part of the system and the program is better for it.

My next point is that services need to be integrated to meet the needs of the long-term care population. The frail older adult has multiple interrelated needs. Medical problems, functional limitations, varying degrees of confusion and disorientation are the norm rather than the exception. Services funded by different programs and delivered by many different providers are not an adequate response. We have seen people going into hospitals because funding wasn't available for a portable meal. Single source access and control over all services is crucial.

A further point is that the provider must be put at risk for cost control. As service providers we are concerned with providing the highest quality of care with the available resources. As taxpayers and political realists, however, we must also ad-

dress the problems of cost control in long-term care. In the present reimbursement system, neither the consumer nor provider has any responsibility for cost containment and as a result costs have gone out of control. Risk-based capitation reimbursement which places the service provider at financial risk has been successfully employed by the Health Maintenance Organizations in dealing with the generally healthy, usually younger, populations. On Lok's experience shows that the same principles can be applied in long-term care with even greater success in controlling the cost and improving the quality of care. Ironically, "HMO-like" programs serving the frail aged, like On Lok's CCODA, do not qualify under existing federal and state HMO legislation because they discriminate based on frailty.

My final point is that special attention must be paid to the plight of the middle-income long-term care needy. The wealthy can buy whatever they need and the poor have Medicaid to help meet long-term care needs, but those with small savings or income have to lose everything before getting adequate care.

The present long-term care reimbursement system most abuses the middle class—who typically shouldered the biggest tax burden during their working days. Medicare insures against the acute hospital bill but for this middle-income group, the truly acute problem is the high, continuing cost for chronic care. Today older persons with modest savings—from two to twenty or thirty thousand dollars—finds very few options when confronted with long-term care needs.

A number of pieces of legislation have been proposed to address the long-term care problems of the middle-income group. Among them are Part D of Medicare, a separate insurance program for long-term care services; expansion of Medicaid eligibility to include the middle income in need of long-term care; and integration of Medicare, Medicaid and long-term care social services into a single authority (e.g., Title XXI).

What is needed urgently is a national long-term care policy which guarantees every individual the right to needed health and health-related services not only in the interest of the individuals but also to control public expenses. The present patchwork of reimbursement only leads to uncontrollable costs.

On Tuesday, November 1, 1983, On Lok began the fourth phase in the development of its long-term care system. On that day, On Lok became the first program in the country to assume full financial risk for delivery of all health and health-related services exclusively to a certified frail population. Through assumption of financial risk, On Lok has an explicit incentive to control cost. Medicare and Medicaid now pay On Lok a monthly fee that is less than these programs' normal costs for this population—so cost savings are guaranteed. Non-Medicaid participants now pay their share of cost for services not normally covered by Medicare. On Lok continues to have freedom to serve individual needs rather than reimbursement constraints and accepts that financial risk is the cost of this freedom.

Our demonstration was authorized by an amendment to the 1983 Social Security Act, for which I'd like to thank members of this committee and others who gave us support. While On Lok has indeed been fortunate in having the opportunity to develop its model long-term care system, On Lok is not unique. There are many other good demonstrations going on in this country and many other providers across the nation have approached On Lok in search of a similar oportunity for better serving the people they care about. Therefore, we urge Congress to support the development of innovative systems of long-term care that address the dual concerns of quality and cost control. Ongoing Medicaid demonstration authority as granted in section 2176 of the 1980 Omnibus Reconciliation Act is a step in the right direction, although there are implementation problems. On Lok has worked with the California legislature's Subcommittee on Long-Term Care and knows well their interest and the barriers they face in establishing better long-term care programs in the state. Congressional support is needed to see that the intent of 2176 is realized at the state level and that similar Medicare waivers are enacted. Furthermore, we must look to these demonstration programs not as time-limited experiments that will be started, stopped and studied, but as ongoing, evolving systems that continually strive to improve the long-term care services and reduce costs.

We must find new, better and more cost-effective programs to serve the aged in need of long-term care and extend these innovations into policy through legislation. We must caution, however, that these programs do not develop in a day, a week, a month, a year or even three years. They take time. Medicare, Medicaid, the states and Congress must work together with providers and consumers to develop more equitable and effective systems of services for our frail aged. It is time for action and we offer you our assistance.

STATEMENT OF ROBERT J. KARR, A CAREGIVER, SAN FRANCISCO, CALIF.

Gentlemen: Respectfully, yet humbly, I dare to approach this committee and demand its attention. I seek from this learned assembly of representatives understanding and answers to the questions of millions who have learned to live with the experience of Alzheimer's Disease but can never learn to live with its attendant destruction of family, career, saving and ultimate bankruptcy; resulting in the total degradation of life, the reduction of medical care, the infusion of despair and the ultimate loneliness of human heartbreak.

Medical practitioners, biologic researchers, students of psychological theory have sought for years for the enlightenment to ease this burden from mankind. However, the subject of research, cause and effect, potential short term neurological relief or long term life restoring cure is not the subject of my appeal today. Instead, I would stand before you and eagerly seek your empathetic solutions to my dilemma and my questions.

I am a middle-aged wage earner, more fortunate than many, yet not wealthy in material terms; certainly a survivor and probably classified as middle income. My home carries a modest mortgage and my savings are few. My five children were educated to the best of my ability, are grown, mature, responsible and, in truth, are my best friends. By general standards, my career is rising and the highest income producing years are yet to be realized. Millions of the people would see me as successful, fortunate, ambitious in family, career and marriage.

But, as I stand before you I must ask why do you force me to degrade my values and divorce my wife of twenty-eight years, the mother of our five children, the lady I chose to live and die with.

Why must I find the legal mechanisms which will allow me to continue giving her the medical care and quality of life, which at its maximum you learned representatives might find unacceptable as minimum care?

How would you tell my children that it is only a legal maneuver that I leave their mother with all our combined assets, knowing that their father must start life anew and find even greater income to provide continued care for their mother, even though governmental funds may be available?

How, I ask, do I destroy the marriage vows of the years, disrupt lives, and, for the first time give my children the example of the antithesis of our natural, most fundamental form of society—the family unit?

Gentlemen, I abhor what I must do. It is contrary to my principles, beliefs and religious customs. Yet, I must do it. Why? Because you, our representatives, have not realized yet that the individual industry of responsible, hard-working people may require financial assistance. With an Alzheimer's Disease experience it not only may, I promise and assure you it irrevocably will and does.

The laws of our nation demand that both my wife and I must become destitute and therefore your wards. However, as long as I have income producing years it is improbable that any form of Federal, State or municipal government agency will recognize my needs and most probable that it will not. You and your peers have destined that all my years of modest ambition will result in the deterioration of life, both for my diseased wife and myself.

Gentlemen, I and millions of others beg you to find a solution to our problem. I ask you not to relieve the stress and anxiety from our daily lives but only to listen to our combined voices, hear our pleas, listen to the needs of your people. We have elected you, we trust you; we have the undying faith of American generations that our system not only will prevail but in its empathy can and will lift the burden of financial and family ruin from our lives.

With this fervent hope I pray to God.

HEALTH CONSERVATION, INC.,
San Francisco, Calif., February 2, 1984.

BILL HALAMANDARIS,
Subcommittee on Long-Term Care,
Washington, D.C.

DEAR BILL: I agreed to submit information that would supplement the material previously submitted to Congressman Claude Pepper's subcommittee hearing of December 15, 1983. I would appreciate it if this letter could be included in the hearing record.

Helping people with home care needs is not always easy. Problems are compounded when people are poor and need government help. In our agencies, a person can be eligible for Medicare, Medicaid, Veterans' Benefits, Older American Act funds,

hospice care and many other government funded services. Each program responds to a need but none of these programs looks at the whole person. The result is fragmented services, costly bureaucracies, waste, and abuse of recipients as well as workers trying to care for the people in need.

Title XX is a federal, state and local program. It has been the subject of repeated exposes in newspapers, television and congressional hearings. Repeated promises are made to change things in this government program, but the problems get worse. In California, this single government program affects over a hundred thousand recipients and eighty thousand workers, costing the taxpayers a half a billion dollars a year.

California's implementation of Title XX, the In-Home Supportive Services Program, is a scandal whereby well paid public employees exploit workers and deny them their employees rights. The predictable result is abuse of the sick, the elderly and the poor. Before I describe the latest abuses, may I respectfully request that an outcome of this hearing be a full and comprehensive investigation into the Title XX relationship to the other government programs like Medicare, Medicaid, Veterans' Benefits, Hospice Care and the Older American Act.

A report of this investigation should lead to new federal legislation which will address the recognized problems of fragmentation and bureaucratic waste and abuse.

The competitive bidding and contracting processes for in-home supportive services have been referred to as "jokes and "shams". Part of the reason for the derision of public employees involved in these processes, is that some companies bid on one basis but execute the contract in quite a different way; sometimes with the knowledge and blessing of well-paid public and union officials.

For example:

The bid specifications may require a specific number of supervisors or an amount for vacation time. There are no know audits to determine the degree of relationship between a bid and actual performance. When material differences between a bid and performance are exposed, there seem to be no penalties or sanctions against the bidder, a contractor or the union and public officials charged with specific responsibilities.

The very concept of "lowest bidder" must be challenged as used in this program because the lowest hourly bidder is going to be the most expensive in total cost—in more ways than one: costly for consumers, taxpayers and workers as well as destructive of the basic belief held by all Americans that fairness and justice are available through our government and unions and their employees.

Lowest cost does not equal lowest hourly or unit price. To determine lowest cost, one must know the unit price plus the number of units (or hours) utilized in a given period of time, a month, for example. In addition, the length of stay must be known (how many months on the service) and the rate of recidivism must be known, that is, does the person get better and stay off the service or are they repetitively back on the service.

Testimony being submitted details continuing scandals in this vital and valued program. The testimonies tell a tale of abuse and waste and ask for a proper congressional investigation to determine if there are crimes being committed and what legislative remedies the Congress should consider.

Remedy Health Services has been a successful bidder on several in-home supportive service contracts in California counties at extremely low hourly rates. This has lead to speculation that in order for the company to make a profit, the company must take short cuts in the program and short change the government and the company's workers in terms of wages and fringe benefits through questionable cost cutting methods. Evidence is accumulating that these cost cutting methods are not speculation but are being used by Remedy. For example:

A. *The Government is short changed:* The union and Remedy agreed on August 16, 1983, after Remedy received the San Francisco in-home supportive services contract that each employee's regular wage rate would be reduced by fifty cents per hour and paid to the employee as a "clothing maintenance allowance". It appears that this method of cost saving is a willful avoidance of federal, state and county payroll taxes and legally required insurances. It is my understanding that a letter to this effect has been transmitted by the San Francisco Department of Social Services to the City and County of San Francisco Attorney who has forwarded the letter to the Internal Revenue Service.

Although this questionable practice may leave a few dollars extra in the hands of the workers, it violates the law and the employer, under such a provision, would save a quarter of a million dollars in unpaid employer required taxes and insurance premiums for things like social security and Workers Compensation, among others.

B. *The Program is short changed:* In San Francisco, there have been three trained and experienced supervisors terminated since mid-August, 1983. One of these employees was a nurse. Another had a professional social work background, and the third was fluent in Chinese. These individuals were replaced by personnel from the company's San Mateo County office, I am told.

The contract in San Mateo calls for ten field supervisors. Indications are that this contractual program need is not being met in San Mateo County because supervisors have been transferred to San Francisco. If I were an auditor, I would want to be assured that there were no double billings or costings as was found in the Souza case of several years ago.

C. *The Workers are short changed:* The union contract between Remedy and the Hospital and Institutional Workers Union, Local 250, requires that only 10 percent of the work force be employed as "casual". The reason for this stipulation is to remove incentives from the employer to hire a large number of relatively short term employees at the expense of the regular homemakers, many of whom have acquired training and experience as well as seniority for purposes of earnings and patient care skills. Indications are that this contractual commitment is being systematically violated by Remedy and that instead of having about 40 "casual" workers, as required by the Union Contract, Remedy has many more than this.

The union signed a "favored nations" union agreement. This "favored nations" clause means that other signators to the union contract can take advantage of benefits granted to a different employer. In this situation it would mean that San Francisco Home Health Service would have to participate in a willful avoidance of federal, state and county payroll taxes and legally required insurances and violate the purposes of having a limit on the number of casual employees.

If I were an investigator, I would want to assure myself that the agreements between Remedy and the Union were properly negotiated and fairly reached. Indications are that there were "sweetheart" arrangements made.

Since regular hours worked at clients' home and hours spent in transit between clients are lumped together on Remedy employee payroll checks, there is a logical suspicion that transit hours could be billed as service hours. If this were the case, it would violate the terms of the county contract and the program requirements. It would also appear, if true, to violate the union contract.

Field supervisors have been admonished to maximize the number of hours that each client receives so that the total contract hours can be raised and thus reduce the fixed cost component of Remedy's budget. For example, historically in San Francisco, the number of hours served is less than 80 percent of the number of hours authorized due to clients being hospitalized, out of town, family visits and other reasons. The result of this type of increase is to raise the cost of services per client per month due to overutilization of services without providing compensating benefits to the client or the taxpayer.

One should note that when workers are shortchanged, so is the program.

In the case cited previously, where Remedy is deducting 50 cents per hour from the employee's regular wages, the employee is being exploited. The employees are underpaying Social Security and Federal and State Withholding Taxes through no fault of their own. When the various taxing agencies require a full payment for back taxes, the workers will be required to pay on these earnings. I have previously submitted to the committee staff copies of court decisions on these matters.

The union contract calls for the employee and the employer to each contribute five cents per hour to an employees' pension fund. The money has been withheld by Remedy, we understand, but no accounting has been given to any of the employees. The question becomes, since the union contract requires that we follow the ERISSA requirements for pension funds: what is happening to these monies.

I understand that Remedy has not explained to its workers how the workers' vacation time is being accrued. In the past, we have known of hundreds of homemakers who have not been paid their vacation by the employer and where the state of California appropriated additional funds to cover this expense following the bankruptcy of a major company.

The union contract requires that employees receive Kaiser Health Plan B Medical Coverage, or its equivalent. It is my understanding that Remedy workers are receiving Plan L, which is not equivalent. It costs the employees more, and the employer less.

The employees have requested that all hours accrued for regular wages, such as travel, sick leave, vacation, training, among others, be listed on the pay checks so that they will know how these benefits are accumulated.

Recently a union member complained to a shop steward of Local 250 that Remedy was not paying appropriate travel time. The shop steward was able to get the local

Remedy manager to admit that Remedy employees had beeen instructed to "short-change" employees some 200 hours of travel time each month, I am told.

It would appear, from several employee complaints, that senior workers' hours are being reduced and that these hours are being replaced by "casual" employees. This, of course, reduces the quality of the program, saves the employer money because they are paying less in terms of wages and fringe benefits and the practice thoroughly demoralizes the existing work force.

In short, it would appear that the problems of Title XX continue. The problems have been well-documented and reforms have been promised repeatedly. Yet, as before, I request your help in obtaining the facts about this company and ask for changes in the current system which seems to encourage dishonest employers such as Gottheiner and Sousa.

I will be glad to work with your staff and others to offer suggested solutions and to get to the root of these problems.

Respectfully submitted,

ROBERT L. LUCAS,
President.

STATEMENT OF PHYLLIS MANSFIELD, FAMILY SURVIVAL PROJECT, SAN FRANCISCO, CALIF.

Ladies and Gentlemen: My name is Phyllis Mansfield and we have lived in San Francisco since 1961, when my husband, Dean, retired from the US Air Force.

In 1970 he and I both noticed a very slight tremor in his left arm. The tremor gradually increased and later that year it was diagnosed as being caused by Parkinson's disease. It is a progressive disease, with no cure in sight yet. Even with medication we were aware of the debilitating effects of the disease—increased tremor of the hands and the mouth—lack of coordination and weakness in both hands and legs. However, until 1978 he was able to play golf, drive the car, attended symphony and opera, take care of himself. In February of that year, I came home from a shopping trip, found him on the floor, unable to get up by himself, altho he had been trying to for two hours. A neighbor helped me get him up that day, and I have never left him alone since then.

He is now mobile around the house and for short distances outside, but his balance is very poor and we do not let him walk alone. He is incontinent at times; he needs help getting out of bed and up from chairs, and also with bathing and dressing and undressing.

When I realized I needed hired help, so that I could get out to take care of all the routine chores, I called on Senior Resources, an agency of the Episcopal diocese. They recommended home health care agencies and we joined one. We started out with a health aide to come for four hours, two days a week. We paid this with no help from anyone.

It was this agency that gave our name to Family Survival Project, a pilot project funded by the State and by private contributions, to provide various kinds of aid to those caring for braindamaged adults at home. In fact, Fam. Surv. Proj. is unique. My reason for saying that is that in April, at the request of Fam. Surv my Proj., my husband, our health aide, and I were subjects in a TV documentary about the aged, produced by television station, WBZ of Boston. When I asked the producer why they had come to S. F. to do this, she said, "Because Fam. Surv. Proj., is the only one of its kind in the United States."

Our aid from Fam. Surv. Proj. has helped us in two ways. First their financial aid made it possible for us to have home health care for four hours every day of the week. Secondly, I have called them several times for advice about health agencies. They are very supportive, calling often and regularly to ask if there are any problems. That is important: to know that someone out there cares and is willing to help. When I fell and broke my wrist last spring, they were able to add some supplemental financial aid.

When we chose to live in S.F. after retirement, it was for many reasons; partly because of the commissary and PX privileges at the Presidio, but more importantly because of Letterman Army Med. Center, where Dean has received excellent medical treatment; It is called "free", but surely earned with service to the country for 30 years in both peace and war—World War II and the Korean conflict. Our only use of medicare has been the rental of a hospital bed.

If Dean's health were to worsen markedly and if Fam. Surv. Proj. funds were suddenly cut off, I would still do everything in my power to keep Dean at home. If we

needed a health aide for 10 or 20 hours a day at the rate we are paying now, we would probably manage for several years, though it would mean sacrifices.

I still remember the sickening feeling I had when I discovered that there was no financial aid for us if I took care of Dean at home. Medicare would pay for expensive hospitalization, but nothing at all for much less expensive care at home. It didn't seem fair to me then, and it still doesn't. Why shouldn't Medicare help pay for this long term health care? If anything I have said here today helps us attain that goal, I will feel as if I had served a good cause.

STATEMENT OF FANNY MAROTTA, SAN FRANCISCO, CALIF.

To whom it may concern:

I am a 68 year old woman whose husband died last year of pneumonia. This cause of death does not begin to describe the disease that really killed him and nearly killed me. In February, 1981 Frank was diagnosed as having Alzheimer's disease. I had never heard of the disease and remember asking the doctor to spell it for me. What could the doctor do to cure Frank? Nothing! What sort of help was there for him? None!

My husband, who had always done the shopping, got lost on his way home. My husband, who was a very clean, fastidious man, no longer wanted to bathe. He put lighted cigarettes in his bathrobe pocket. He mistook the living room for the bathroom and urinated on the carpet. In the middle of the night he wandered around the house and ate anything he could find. During the day he dozed. Every minute it seemed I had to be alert and watch him for fear he would hurt himself or cause major damage to our home, which we were still paying for. My blood pressure soared to alarming heights and my artificial hip made it nearly impossible for me to help Frank in any physical sense. Once I finally convinced him to get in the bathtub, but I could not help him out. He was stuck for a couple of hours.

For over a year I cared for my husband night and day without any help. My children live on the East Coast and couldn't help me either. I couldn't afford any help for fear I would have to spend all our savings eventually on a nursing home. Over $2,000. a month is what they cost. Medicare and his insurance would not pay for anyone to help bathe him, would not pay for any sort of day program, would not pay for someone to even sit with him while I went out for groceries. Our life was a living hell and financial disaster was what we looked forward to.

Finally, the strain was so great that I risked being hospitalized. An acquaintance owned a small rest home and agreed to take Frank. At the end of a month she had to raise the price another $100 to pay for extra help to care for him. At the end of the second month he needed to be hospitalized with staph infection. He died a few weeks later.

It wasn't until Frank got the infection that insurance covered care for my husband. Over $12,000, it cost for those last couple of weeks. I would have rather seen some of that money spent for care at home, for respite, for home health aides for Adult Day Health centers which could accommodate people like Frank.

I would testify in front of you today, but I am still recovering from the stress of the last couple of years. I am depressed and have no energy. I will always be angry that there was no way the "system" helped my husband and I when we needed it most.

CALIFORNIA CONFERENCE
OF CATHOLIC CHARITIES DIRECTORS,
Sacramento, Calif., November 10, 1983.

Hon. SALA BURTON,
450 Golden Gate Avenue,
San Francisco, Calif.

DEAR CONGRESSMAN BURTON: Last month 900 representatives from all over the United States met at the National Conference of Catholic Charities meeting in Baltimore. The group unanimously passed the attached resolution on Health Care for the Aging which was written by the California delegation.

I know you are concerned as we are about the high costs of medical care and the burden those costs place on elderly people.

You will be especially interested in our recommendations on page two of the resolution for the Medicare program.

I hope you will give serious consideration to our position and be a strong advocate for maintaining and improving coverage for older Americans under Medicare.

Sincerely,

JAMES PURCELL,
President.

Enclosed.

HEALTH CARE FOR THE AGING

Whereas, in Pacem in Terris (No. 11), Pope John XXIII listed medical care as a human right which promotes the development of life; and

Whereas, in their Pastoral Letter Health and Health Care the United States Catholic Bishops also consider health care a basic right which flows from the sanctity of human life (I), and encourage us to model health care delivery after Jesus' personalized contact with people who were sick, suffering or requiring care; and

Whereas, the Bishops further explain (II-A) that from the biblical prespective health means wholeness—physical, spiritual and psychological; individual, social and institutional; and

Whereas, the National Interfaith Coalition on Aging also uses the word "wholeness," which is furthered, they state, by "the affirmation of life in a relationship with God, self, community and environmental"; and

Whereas, Neither Pope, Bishops or Coalition qualified health care by age or economic condition. Rather, they affirmed its right to exist in a comprehensive manner, at every stage of the life cycle, by nature of man's very existence as a human being; and

Whereas, the heritage of healing ministry, therefore, must be personal, foster wholeness, be integrated and comprehensive in its scope, and be renewed and adapted to the needs of today (Health and Health Care, II-b); and

Whereas, access to health care in America is a right to which all people are entitled; and

Whereas, economic conditions, current public policy directions, and inadequate community based long-term care services have a profound negative effect on the health of the Aging in America; and

Whereas, our country's present, profit-oriented health care system does not provide adequate, affordable or accessible care; and

Whereas, older people, as the major users of health care services, not only suffer the high costs of medical care, but are victims of financing mechanisms geared to an acute care "sickness model" which is not congruent with their more chronic health care needs; and

Whereas, our Nation currently has no universal system of health care; and

Whereas, the current "crisis" in the financing of the Medicare system is not engendered by the graying of America—rather it is brought on by open-ended government funding of private health care services; that is, by government adopting indemnity insurance principles and financing techniques in the reimbursement of health care of the Aged: therefore,

Be it resolved, That the National Conference of Catholic Charities confront the complex social, political and economic issues surrounding health care for the elderly by taking action to halt government assaults on the Medicare system, especially proposals that would seek cost containment by increases in beneficiaries' share of cost or reducing the care they receive;

That the National Conference of Catholic Charities *oppose* any changes in the Medicare system that would place a heavier burden on the consumer by:

Reducing eligibility and benefits directly affecting beneficiaries

Increase co-payment and deductibles

Instituting means testing for eligibility

That the National Conference of Catholic Charities *support* Medicare revisions that would:

Control costs at their source, both institutional and individual providers reimbursement

Require physicians to accept Medicare assignment without charging additional fees

Reimburse for services such as annual physical examinations which promote health and prevent disease

Reimburse for long-term care services, including adult day health care and social rehabilitating adult model day care, hospice services, respite services, more in-home services such as para-professional homemaking and case management services

Provide for out-of-institution drugs, eye glasses, dentures and hearing aids

Explore alternative delivery systems, especially Social Health Maintenance organizations

That the multiple dimensions of long-term care become a focal point for mutual concern and cooperative action by the Church's formal charity and health apostolates

That Catholic Charities agencies and program support and assist Parishes to take part in the continuum of long-term care by developing services which enable families to care for their sick members.

MEDICARE REFORM—LILLIAN RABINOWITZ

The years 1981, 1982 and 1983 have brought burdensome changes for health care provisions for older American adults Medicare. The recommendations of this Administration for the years ahead seem to project an even more fearsome prospect for this population. Between larger deductibles and co-payments, many elderly are, or will be, having to choose between paying health-related bills and/or decent shelter and nutrition. Essentially these brutal plans entail shifting costs from the federal government to the already hardpressed consumer.

Because of our regressive tax base and our Administration's course aimed at world hegemony through the threat of nuclear assault, the needs of our vulnerable elderly have low priority for response. Indeed, if you will permit me to coin a word, we seem to be moving toward geroutocide. Our death camps for the elderly are not gas chambers, but poorly monitored, for-profit nursing homes. Or, more subtly, perhaps, a set of policies and regulations making appropriate and affordable health care increasingly less accessible.

Among measures which should be taken in the short run are the following:

(1) Make it mandatory for physicians treating the elderly to accept Medicare assignment;

(2) Support community clinics with emphasis on preventive health care and maintenance therapy for those with chronic illnesses;

(3) Make Adult Day Health and other Long-term Care services Medicare benefits, thus providing humane, cost-effective options to premature institutionalization.

Findings from our Over 60 Clinic point to the importance of providing two kinds of service now excluded by Medicare, i.e., dental care and podiatry. Currently, dental care is provided only in cases where maxillo facial surgery for pathology such as cancer is present, etc. Yet much illness both physical and mental can result from the deprivation of good oral health. Persons who are edentulous cannot eat the kinds of food required for good health; moreover the loss of facial contours and the disfiguring affect of loss of teeth causes many elderly to avoid all socialization and leads to depression.

Our Over 60 Clinic has been granted the services of a dentist from the National Dental Services Corporation for two years. We provide care, both free for Medicaid recipients and for others on a sliding scale basis. Although this service began only a few months ago we have a two-month waiting period already. We are inundated with clients who have had to do without dental care for years because of cost barriers.

Our Clinic also provides some podiatry, done by geriatric nurse practitioners who have been carefully trained by a podiatrist to perform limited procedures. But podiatry is not provided under Medicare except in the cases of pathology caused by severe diabetes, advanced vascular disease and persistent fungal infections. Yet many elderly are unable to care for their feet due to arthritis, or poor vision, for example. Frequently elderly are severely handicapped by painful conditions such as ingrown toenails, bunions, and warts which make walking painful. Thus they forego exercise and became virtually housebound, leading again to deteriorating physical and mental health. Yet private pay podiatry is often out of the reach of those on low fixed incomes.

Even those elderly who buy various Medigap policies usually find to their chagrin that both podiatry and dental care are excluded.

Many of the exciting health care benefits for the elderly are fragmented and therefore more costly. What is needed for all of our citizens, not only the Medicare-entitled, i.e. the elderly and/or the disabled, is a comprehensive National Health Service such as exists in all industrialized nations except for the United States and South Africa.

In September of this year the National Health Service Act, H.R. 3884, was introduced in Congress. It would reorganize all health care resources—personnel, equip-

ment and institutions into a coordinated health care system to provide health care as a free public service. Financing would come from a health service tax on taxable income of individuals, estates and trusts, and of corporations, according to ability to pay.

Gray Panthers have given their strong support to this measure as a means to help us become a more caring, peaceful and healthy society. We ask for your vigorous advocacy.

MARGOT SALVINI, SAN FRANCISCO, CALIF.

My name is Margot Salvini. My grandmother, Eva Olsen, is 85 years old and was diagnosed as having Alzheimer's in August, 1983. Until this diagnosis my family noticed a change in my grandmother—she was becoming confused, forgetful, and negligent in her personal care and in doing such things as cooking for herself. The confusion, forgetfulness, and negligence has gotten worse to the point of my grandmother wandering away from her home and having to be brought back home by neighbors.

This situation has put a tremendous strain on my mother and myself who are the primary caretakers for my grandmother. We have had to have someone come in during the day to stay with my grandmother and cook for her, bathe her, help her dress, and essentially watch over her. In the evening both my mother and myself stay with my grandmother—this is after both of us have worked for eight hours and commuted from Oakland where we live and work.

Not only are we experiencing the physical strain of providing care, but also the emotional strain of seeing my grandmother as she is now and feeling frustrated, angry, and guilty. Frustrated because there doesn't seem to be anything that can help my grandmother. Medication don't seem to help and there aren't very many programs that would allow my grandmother to participate because she does get combative, she does become incontinent, and she does wander. The anger I'm feeling is at times harder to deal with because I find myself becoming angry at my grandmother and her behavior. I want her to stop acting so combative and so resistant, and puting my mother and myself through this strain. I guess this is because I don't quite understand what's going on with my grandmother. I see her and she looks healthy and strong, but her mind is not there and I only wonder why.

I don't know how much longer my mother and myself can put up with this, but we are going to keep trying. We have looked into nursing homes and decided that this will be the final alternative to dealing with the problem. We want to keep my grandmother in the home that she has lived in for over 50 years and have found out that this is going to cost since Medi-Care won't pay for anything at this point. We have been paying for someone to come in during the day and hoping that we could get some of this through Medi-Care but found out we couldn't. Even a nursing home at this point would have to be paid by us. This is an additional strain that we have to deal with because we are eventually going to exhaust my grandmother's life savings and some of our own savings.

I hope that as a result of this testimony the Administration will really stop and think about what the elderly are faced with and think of what they can do to allow the elder person to live his life with dignity.

RODNEY C. TAYLOR,
Oakland, Calif., October 13, 1983.

Supervisor WENDY NELDER,
President, Board of Supervisors,
San Francisco, Calif.

DEAR SUPERVISOR NELDER: As you well know, the In-Home Supportive Service contract, funded under Title XX, has been a major concern of senior, blind and disabled persons throughout this City since it was awarded to Remedy Home and Health Care Services.

The problems began for each and every client and employees of Remedy from the very onset of the award. These problems, I feel, should be brought not only to your attention, but to the attention of all public officials, from the Health and Human Services Administrator to the Director of the Social Services Department here in San Francisco. Because, if it is not, these problems will fester into a very ugly situation or, a most embarrassing concern for the City.

I was an employee for Remedy as a field supervisor from August 16 until Friday, October 7, 1983, at which time I was called at home after 5:00 p.m., by the program

director, and informed that I was terminated for rather vague reasons, which is altogether a different issue, which I will deal with separately, and in a legal procedure. So, as you can see, I have first hand knowledge of these problems. Specifically, they are as follows:

1. Most of the clients were directly affected with an all encompassing redistricting of the City into compacted areas by Remedy. Most clients had to deal with a new supervisor, a new homemaker, or both. This occurred after Remedy had made assurances to all clients that they (Remedy) hoped to retain all of the clients present providers, should they wish. (See attached letter)

2. Most homemakers were affected by the change in that they got a new supervisor or were removed from long standing clients, which is disastrous, because it takes a long time to build a client/homemaker relationship based on trust and confidence. Some clients have even discontinued their homemaker services due to the disruption in their services.

3. Supervisory staff were also redistricted in some cases, losing once again the client trust. We were told that the redistricting was done to reduce the amount of travel time which, as I see it, also reduces the amount of money paid to the homemakers for travel time. This minor cost saving measure has been done at the expense of the clients and homemakers long standing relationships and well being.

4. Remedy also cut supervisory benefits. i.e. fast passes. This was budgeted into their bid proposal (page 92, item J-1). Where is this money going if it is not being used for fast passes for the supervisors?

5. Last minute union contract additions were made between Local 250s representative and a Remedy official. Without prior agreement from the shop stewards or members, a fifty cent per hour deduction is being made from the homemakers hourly wage and placed into a non-taxable clothing maintenance allowance, resulting in and producing mass confusion among all staff. We did not know that the homemakers were going to be receiving such an enormous allowance to keep their clothing in good shape. The homemakers were not aware that they would be receiving fifty cents an hour less for their work. Their "net pay", in some cases, is greater than their "gross pay", encouraging them to seek assistance from their supervisors as to the legality of this questionable transfer of wages from a taxable status to a non-taxable status. Every inquiry I have made concerning this transaction has confirmed my belief that it is an illegal tax evasive measure for which the homemakers will pay for at the end of the year when they file their tax returns. How much money is Remedy saving in their tax payments is one of many questions that still goes unanswered. If they are cheating here, where else are they cheating?

Unfortunately, Supervisor Nelder, I feel the real issue at hand is the overwhelming neglect that the senior, blind and disabled are experiencing at the hands of the present contractor. Statements to that effect can be obtained from most any client in the program at this time.

Finally, I hope that you do not read this letter and think it a vendetta for my termination. I am personally relieved that I have now the freedom to come forth with this insight to you and others who should know what is happening with this contract. It is out of sincere thoughfulness for the clients in this program that I come to you with what I think are improprieties within the contract since its award to Remedy. It is only the clients who will continue to be abused, not me, not you.

Thank you for any steps that you may further wish to take in this matter. I certainly hope that there is something which can be done. Please feel free to contact me concerning these problems at 635-8924, or 4874 Shetland Avenue, Oakland, California 94605

Very truly yours,

RODNEY C. TAYLOR.

REMEDY HOME AND HEALTH CARE, INC.,
San Francisco, Calif., August 10, 1983.

DEAR CLIENT: Remedy Home & Health care, Inc. is very pleased to have been awarded the In-Home Supportive Services Contract by the City/County of San Francisco. Our services to you are set to begin August 16, 1983.

There will not be a change in the type or hours of service you are presently receiving unless recently changed by your social worker. Additionally, it is our hope to retain your present provider, should you wish to do so.

Remedy will employ, train and supervise your providers and, if necessary, improve the services you are currently receiving.

Following are a few of our policies that will help you to understand the program and will help us in providing you with good service.

1. The client must provide all cleaning supplies—brooms, mops, vacuums, toilet brushes, etc.

2. Providers are not allowed to do any heavy lifting, moving heavy furniture, washing windows on the outside, painting or any major repairs. Strenuous activities also are restricted.

3. Providers are not allowed to do yard work (unless authorized by the County) or canning.

4. Providers are not allowed to climb on footstools or anything that could cause them to fall.

5. Providers are not allowed to transport a client (unless medical transportation is authorized by the County).

6. To ensure continuity of service to all of our clients, changes to the Provider's schedule may only be made with the REMEDY Supervisor.

7. It is very important that you be at home when your Provider is scheduled to be there. He/she may have a tight schedule to meet and it would be very difficult to come back at another time. If you can not possibly be at home at the scheduled time, give your Supervisor a call at REMEDY who will notify the Provider, therefore, avoiding unnecessary expense.

8. When your assigned Provider is unavailable to work, a substitute Provider will be assigned in order that you receive uninterrupted service.

9. Do not ask your Provider to leave lanudry unattended in a public laundromat while performing other tasks.

10. Where errands are an assigned duty, the Provider is allowed to make only one trip per week. The Provider must go to the nearest supermarket, pharmacy or laundromat.

11. At no time is a Provider allowed to purchase liquor for a client.

12. Please do not ask your Provider for his/her home telephone number.

13. Providers are not allowed to work in the home when the Client is not there.

14. Each time your Provider comes to help, you will need to sign the timesheet as proof of the assigned tasks and authorized hours are completed. If either of these are not completed, please call your Remedy Supervisor.

15. If Providers are assigned to do shopping or errands which necessitate the handling of money, a receipt will be issued.

16. Do not ask your Provider to perform tasks other than those assigned.

17. If your assigned Provider fails to show at the scheduled time, please be sure to call your Remedy Supervisor.

We hope you and your Remedy Provider will have a long, compatible working relationship. We work hard at trying to please all of our clients and will assure you that any problem or situation of concern to you will receive our prompt attention.

We want you to know—we really care!

Sincerely,

REMEDY HOME & HEALTH CARE, INC.

TO LOCAL 250 10/5/83

We, the workers at Remedy and union members, are very unhappy with many things since the contract was changed in August to Remedy. The things we want to know or have changed are

1. no 50¢ deduction on our paychecks for clothing maintenance. we want our paychecks to be paid at the rate in the union contract. we did not agree to have this 50¢ deducted from our rate of pay and paid as a non-taxable item. we do not want to have to pay taxes at the end of the year for this amount.

2. all hours are to be listed separate on our paychecks. we do not want our travel time to be included with our client hours. we cannot figure our checks out.

3. we want the clothing maintenance and the pension fund to be based only on the hours we work for our clients. This is how it was set up in the contract.

4. we want running totals of how much we have been paid for clothing maintenance and how much has been deducted for the pension fund, just like we get a running total of how much taxes we have paid.

5. we want to have copies of our time slips. we have to spend money to make copies of our time slips. we cannot figure out our paychecks without copies of our time slips.

6. we want to know when we will have a dental plan. we want to know when the kaiser coverage is effective.

7. we want to have a box at the office where we can leave our time slips after 5:00 o'clock.

8. we want to know when our pension fund will be set up and who is going to pay for all of the interest we have lost since our first paychecks. Who is going to be in charge of this pension to make sure that all the money deducted from our paychecks is going into this pension?

9. we want to know how Remedy is going to accrue our vacation time.

10. when there are mistakes on our paychecks we do not want to wait days and weeks for them to be corrected. we want them corrected the same day.

11. some of our hours have been cut and we want to know how long we have to wait for more hours of work. We were told we would now lose any clients and everything would be the same as before.

Many of us have already complained to Remedy about these things but we do not get any answers. We are asking you to represent us and fight for the things which we think we should be getting. We want answers to these problems and we want them in writing by the end of this week.

LOCAL 250 MEMBERS:

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

TO ALL REMEDY HOMEMAKERS 10/5/83

As your shop stewards we have met with Remedy many times to complain about out paychecks. We have also gone to city hall to complain about our paychecks. The things we are asking our union to help us with today to get changed are

1. no more 50¢ deduction on our paychecks for clothing--we want it paid at the right rate of pay.
2. all hours are to be listed separate on our paychecks. Client hours, travel hours, sick hours, etc.
3. we want the clothing maintenance and the pension fund to be based only on the hours we work for our clients. This is how we set it up in the contract.
4. we want running totals of how much we have been paid for clothing maintenance and how much has been deducted for our pension.
5. we want to have copies of our time slips.
6. we want to know when we will have a dental plan. we want to know when the kaiser coverage is effective.
7. we want to have a box at the office where we can leave our time slips after 5:00
8. we want to know when our pension fund will be set up and who is going to pay for all of the interest we have lost since our first paychecks. Who is going to be in charge of this pension?
9. we also want to know how Remedy is going to accrue our vacation time.
10. when there are mistakes on our paychecks we do not want to wait days and weeks for them to be corrected.

If there is anything else you want us to do now or later please call any one of us.

WE URGE YOU TO MAKE COPIES OF YOUR TIME SLIPS UNTIL WE CAN GET A COPY FOR US. We have made up a form for you to use when you do have a complaint. It is important that you make a copy of any complaint that you make.

If you need help with understanding your paychecks you can mail your checkstubs or a copy of it to us and we can try to explain it to you.

We must stay together for our fight for what we want and what we have earned.

Lula Taylor 863-2571 | Lucille Hayes 552-9766 | LeeDora Neal | Cyril Titeng

TESTIMONY SUBMITTED BY ARTHUR WOLF, ASSISTANT DIRECTOR, FAMILY SURVIVAL PROJECT, SAN FRANCISCO, CALIF.

The Family Survival Project for Brain-Damaged Adults is a support organization for the families and friends of adults with chronic brain disorders. Since 1980 we have operated a state pilot project for the California Department of Mental Health, under which we have undertaken such services as intake screening, information, advice and referrals, in-home supportive services and respite care, legal consultation, group therapy, monthly family support group meetings, training, public awareness and program development. Since 1982 we have been designated by the state of California as the statewide information clearinghouse on brain damage.

As an organization working on a daily basis with the problems confronted by brain-damaged adults and their families, we have come to recognize that nearly all families caring for adults with permanent, severe brain damage confront similar problems, no matter what the cause of impairment or disease. Such problems result, in large part, because:

No insurance policy—not even Medicare—will pay for the care which must be given. Less costly community care programs are often not available, resulting in an estimated cost nationally of at least $20 billion a year.

Few professionals realize the immense needs and the creative solutions required to help victims, their spouses, parents and children.

Families often break under the strain of grief, 24-hour care demands and social stigma of "brain damage."

Particularly when dealing with the population afflicted with dementing illness, the family—not the individual—is the level at which much of the intervention must be targeted and where uncovered need is the greatest. However, public services and income benefits have traditionally been withheld when the family retains a caregiving function, as opposed to relinquishing care to an institution. A review of public services and their availability to this population points out the limitations of current programs.

Medicare: Diagnostic, acute care and immediate post-acute care services only are provided (except in waiver demonstration projects). Once a chronic organic brain disorder is diagnosed, only other treatable illnesses can be covered by Medicare on a short-term, limited basis.

Medicaid: While services vary in each state, reimbursement of nursing home care is generally provided if a facility will admit a dementia patient; if a facility will accept the rate of reimbursement offered; and if the facility will accept a Medicaid patient (i.e., has not met its "Medicaid quota"). Medicaid programs do not cover home care except in certain waiver demonstration projects). Although Medicaid will reimburse for day care programs, few such programs are able to accept dementia patients.

Title XX Social Services: Many recipients of County-provided social services find their share of costs for home care services to dementia patients to be higher than the value of the services authorized. Also, the type of service offered is usually inadequate for patients that are very near nursing home placement. Respite for family care-givers is not generally included in the concept of in-home supportive services to adults.

Older Americans Act Programs: Theoretically, Title III Supportive Services should be available to this population, especially in-home supportive services, case management and day care. To date, with few exceptions, these programs have been unable to meet the needs of this population.

The full range of needed programs, not all of which are health care programs, are:

In-Home Supportive Services: Caregiver assistance is needed on an on-going basis. Alzheimer's and other dementing illnesses are chronic in nature—not acute—and the need for care increases over time rather than decreases as health is regained (the acute-post acute model on which Medicare coverage is based). Depending on the abilities/disabilities of the caregiving family unit, in-home service needs may include: home health care (e.g., administration of medications, physical therapy), homemaker/chore services, transportation, and/or personal care services (feeding, grooming, transferring).

Out-of-home respite: Beyond assistance in the home or in lieu of such assistance, caregivers need programs which will free them temporarily from caregiving responsibilities. These may include:

Day care programs especially designed for the Alzheimer's patient, and

Respite care beds in institutions that can be used on a daily or weekend basis.

Legal and Financial Counseling: To plan for care over the long haul and to maintain the legal/financial health of the family for the longest period of time.

Patient Care/Behavior Management Training: To equip family caregivers with the skills to do the job that has been thrust upon them and to cope with the difficult problems presented by the Alzheimer's patient.

Institutional Care that is Tailored to the Needs of the Alzheimer's Patient: Because these patients may be physically mobile and disoriented, locked facilities are essential; exercise is important in relieving the agitation of dementia patients, so safe areas for "wandering" are desirable; adequate staffing to assure the safety of all patients from the violent outbursts sometimes seen among dementia patients is critical; Medicaid rates of reimbursement certainly do not foster such specialization.

Mental Health Services: For the caregiver, to relieve that strain and grief experienced in the process of constant caregiving and/or placing a loved one with Alzheimer's and related diseases.

In order to help the Congress address such needs, we support the cooperation between and coordination of Federal, State and private health insurance programs to ensure that brain-damaged adults, their caregivers and families receive the most appropriate programs and services to meet their individualized needs. Toward this end we urge:

Efforts by Congress to initiate a national, catastrophic health insurance program that includes coverage of care for brain-damaged adults.

A study of the feasibility of allowing health policy holders to "pool" available private and publicly-funded benefits for use as they determine and without limitations based on "type of care." Support the concept of "voucher" utilization to further flexibility and individual determination of choice of programs and services.

Changes in Federal policies of the Health Care Financing Agency (HCFA) and Medicare so there will be reimbursement for care of persons with chronic brain disorders.

Federal policies which permit recipients of SSI/SSP to continue receiving such income maintenance benefits for a period of time after earning the maximum amount of wages which would terminate the benefits (e.g., up to three months beyond the cut-off point).

Changes in Federal policies which do not require the "spend down" of assets in order to qualify for income maintenance such as SSI/SSP when one member in a marriage partnership becomes permanently and severely brain-damaged.

Family Survival Project also supports public policy that ensures data collection related to organic brain disorders and damage when such is based on uniform terminology, definitions and semantics and is not violative of confidentiality statutes. There is currently little consensus over the diagnostic categories used to describe organic brain disorders, and without such consensus an accurate estimate of the number of Americans with these impairments is unavailable.

We further believe that government should ensure that there are regional "clearinghouses" within each state for information and referral services and up-to-date placement assistance and information.

Finally, we support volunteer, paraprofessional and professional training and advocacy assistance for brain-damaged adults, their caregivers and families and endorse a joint, public and private initiative to ensure that such resources exist. It is only when these objectives are accomplished that a truly comprehensive system will exist to help alleviate the emotional and financial burdens now placed upon the families of those unlucky enough to have to care for a brain-damaged family member.

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ALTERNATIVE METHODS OF PHYSICIAN REIMBURSEMENT UNDER MEDICARE

As one of the founders of the Medashare for Medicare Program, I have been requested to give testimony regarding alternative methods of physician reimbursement under Medicare and other cost-containing concepts relevant to the long-term care of patients.

All written testimony and literature regarding health care in these United States of America is currently directed toward producing a negative health care policy. There is NO constructive health care policy in this nation. All efforts and all available discussions on this matter are directed toward decreasing costs, reducing utilization, decreasing services and under the disguise of centralization, reducing access

to medical care as well. Decrease utilization, reduce services—all negative terms resulting in a negative health care policy. This policy is being proposed at a time when 11 percent of the population of the United States of America is 65 years of age and older. This population accounts for one-third of all health care costs and by the year 2000, 12 percent of Americans will be over the age of 65, more than 25 percent of them will be in their 80's.

Of all of the people in the history of mankind who live to be 65, half of them are alive today and one out of every four babies born in the United States today will live to be 85 years of age. It must be appreciated that people over the age of 65 require visits to their physician four times as often as those under the age of 65. In this arena, we hear medical economists and congressmen endeavoring to create a Negative Health Care Policy for the United States of America.

A generation ago, computerized tomography, ultrasonography, arthroscopy, fetal monitoring, laser beams and pacemakers, microsurgery and nuclear radiology did not exist. There were no organ transplants. There were no intra-ocular lens implants and there was no microsurgery. In 1967, 650 people in the United States were on kidney dialysis and in 1980, the number was 64,000. Approximately 150,000 pacemakers are implanted each year in the United States.

Modern technology is clearly enabling more people to live longer and fuller lives than ever before and the longer they live, the greater the demands on the health care system and the greater the costs. In this milieu, our economists and many of our congressmen are urging the development of a Negative Health Care Policy for this country.

HEALTH CARE, A GROWING INDUSTRY

A great deal of attention has been given to the growth of the health care industry which is estimated to represent 10% to 12% of the Gross National Product. Many point to that figure and demand cost containment, which we agree, is essential. Clearly, we would like to see better cost containment for health services by reason of more efficient utilization, but the 10% figure is grossly misused. The health care industry has simply performed, as the nation has desired the rest of the nation's economy to perform. Had those other areas of the economy such as the steel industry, the auto industry, the agricultural industry, etc. grown at a desired rate, the health care industry segment of the GNP would represent a much smaller proportion.

EXCESSIVE ADMINISTRATIVE COSTS

In terms of real cost containment, one must look specifically at where the Medicare dollar is spent. Physicians receive 17-20 percent of the Medicare dollar. However, the administrative costs of the Medicare Program represent 52% of that dollar. The balance of approximately 30% is paid to hospitals, x-ray laboratories and other provider facilities. It is clear that administrative costs represent the largest proportion of Medicare expenditures.

In addition, a study in New York State indicated that hospitals were spending 25% of their budgets to meet local, state and federal regulations. This study found that expenditures amount to 1.1 billion dollars, that each registered nurse spent the equivalent of one day a week on regulatory matters and that $38.86 of each patient daily bill was generated fulfilling regulatory requirements. This is in addition to spending over 50 percent of each Medicare dollar on the administrative aspects of the program. Clearly, this has to be viewed as unconscionable.

In the 1940's, the Hill-Burton Act was the response to a shortage of hospital beds; in the 1950's, voluntary planning agencies were established to address the issues of coordination of hospital services; and jumping to the 1970's, regulatory controls are flourishing to grapple with the problem of spiraling costs within the voluntary community hospitals. This myopic and spasmodic process obviously leaves much to be desired.

It is perhaps at the national policy level where misdirected focus is most clearly evident. While the federal government is articulating policies aimed at increasing the availability of preventive, ambulatory, and long-term care services and decreasing the emphasis on traditional acute care, in-patient hospitalization, the regulatory procedures it supports have stimulated the opposite effects. Their very efforts to control the health care industry have diverted costly dollars into this arena. For every new regulation, a new administrative structure appears on the regulatory side and additional personnel to cope with the regulation arise on the provider side. As these regulatory endeavors increase, there continues to be a disproportionate effort

and a greater percentage of the GNP being utilized to deal with an increasingly narrower portion of the health delivery system, namely the medical care dimension.

A cost-containment imperative clearly prevails, but the federal center of gravity has not shifted. Governmental focus has merely widened to embrace both regulation and competition.

A veritable upsurge in regulation can be expected on the state level. "Deregulation" is a federal catchword, and a large part of its attendant philosophy is rooted in shifting federal controls to lower levels of government. Block grants, freedom-of-choice waivers, Medicaid "prudent buyer" concepts, and other recent legislation relies on state oversight, and the history of health care portends active—if not enthusiastic—state participation in regulatory activities. For example, 96 of the 164 different agencies that regulated New York hospitals in the late 1970s were state agencies.

Finally, the very nature of recent legislative changes presages more, not less, regulation in program implementation. It is here where large drastic savings can be made. Emphasis in the past and even currently, is being placed on decreasing the expenses created by the providers. Should this trend continue, less will be provided. If greater emphasis is placed on the enormous abuse resulting from excessive administrative costs, then clearly, more services, more access, more utilization, could be provided in the health care industry.

It would be anecdotal to state that if an unpaid robot were able to pay all submitted claims for Medicare benefits and without scrutiny, blindly issue checks for payment, that the cost of health care would almost have to double before the Medicare budget would reach its present level. Whether anecdotal or not, many a true word is spoken in jest.

The net result of streamlining the health care administrative system would be to free massive amounts of money which could then facilitate the delivery of health care services to Medicare beneficiaries and others disenfranchised by economic circumstances.

TESTIMONY ON HMO'S AS AN ALTERNATIVE SYSTEM

Cut costs, reduce utilization and decrease services. This cost saving policy can most efficiently be accomplished by a capitation system which has been popularized as HMO. The term "HMO" stands for Health Maintenance Organization and clearly promotes a negative health care policy. This terminology was most appropriately created to meritoriously advocate the HMO. In may opinion, HMO should in fact stand for "Health Mis-Maintenance Organization".

In should be apparent that pre-payment capitation programs, while cost effective, are so at the expense of drastically curtailing medical benefits. Medical economists have urged that the program be further popularized because, from an economic, standpoint, they appear to be cost-effective. However, such cost effectiveness promotes, encourages and demands deletion of services. If physicians and other providers are to be paid a given fee in advance of rendering their services and if this fee is to cover the entire medical care of a given patient, it stands to reason that as little as is possible will be done for that patient. Profits, both real and in terms of provider time, will motivate that less be done rather than more be done on behalf of the patient. Contra-wise, it may be said that under the present fee for service system, the impetus and incentive is to do too much. If that is true, then certainly it must also be understood that the impetus and incentive under the capitation program is to do too little. Is this what is meant by health maintenance or is this better defined as health mis-maintenance?

The "yard-stick" by which the two systems are compared has always been patient mortality. This appears in the limited studies available to be same in both systems—Fee for Service and Capitation, and this only demonstrates the high level of technical care that science has achieved. The increased technical efficiency of health care services along with other factors has allowed the capitation system to sacrifice benefits to patients without affecting their mortality figures (the bottom line).

With the fee for service system, it should be possible to invoke an effective peer review program so as to render it cost-effective and to avoid abuse. This has not been done to date, but this failure should not be utilized as an excuse to gravitate into a system wherein increasing rewards would be related to decreasing utilization and decreased services. Such a system appears to function because it has and *only* because it has compared itself, for standards of care, to those services rendered by the larger fee for service medical establishment.

Were the reverse true, medical services for this, the most prosperous nation in the world, would progressively depreciate.

Among the disadvantages to patients belonging to an HMO are:

1. The inability of the patient to select the location of the treatment.
2. Long waiting periods for non-emergency healthcare services.
3. The inability of the patient to select who their physician or surgeon will be.

If this type of plan is desired by America—so be it. If this is what is necessary for financial salvation—so be it. However, let us not be like the ostrich and profess that it will provide equal medical benefits. Let us, if we must, offer such a plan with our eyes wide open and with the full knowledge of what the costs are in terms of reduced medical benefits. We, the American public, will pay dearly should such a plan prevail and perhaps even more importantly, we will pay a yet heavier price in the limited expansion of medical science and the diminished treatment capabilities of the medical establishment as a result of such restrictive incentives.

MEDASHARE FOR MEDICARE

Medashare for Medicare is a non-profit program of the Senior Healthcare Foundation, which is a charitable organization. It is designed to bring together recipients of Medicare and a comprehensive network of physicians and other health care providers who have contracted to accept the Medicare assignment of benefits as full charge for services in accordance with Medicare rules and regulations regarding deductibles and co-payments. Approximately 200 physicians and four hospitals have joined the Medashare Program to assist Medicare recipients. The physicians represent all specialties in the field of medicine and surgery from heart surgeons to family practitioners, podiatrists to dermatologists, etc. Virtually no aspect of medical care is left uncovered by this program.

The physicians and other health care providers agree to accept Medicare assignment and after receiving the allowable reimbursement payment in accordance with Medicare regulations, bill the patient for the 20 percent co-payment. If the patient has some form of supplemental insurance or has the means to pay, they are urged to pay the co-payment as required by Medicare requirements. The physicians agree to allow those patients who wish to pay co-payments and deductibles on an installment basis with no carrying charge. However, if the patient does not have insurance and if they are clearly unable to afford the co-payment because of serious financial distress, the co-payment may be declared "uncollectable" and the patient will receive no further billing. This is in accordance with Medicare regulations.

Medashare provider hospitals have agreed to reduce the Part A deductible upon admission by one-half. In addition, they allow the patient to pay the balance of the deductible and that portion of Part B services which are not reimbursed by Medicare, on an installment basis without a carrying charge. Medashare patients are not asked to pay in advance of any medical treatment or hospitalization and there is no charge for enrolling in or maintaining membership in the Medashare Program.

Because of these special financial arrangements, all seniors covered under Medicare, have equal access to quality healthcare regardless of their ability to pay advance fees, deductibles or co-payments. Participating seniors needing medical treatment no longer fear the burden of economic calamity in their lives and freely seek required medical care. The benefits of early detection and treatment of disease, both in terms of lives and healthcare costs are obvious.

The Medashare Program, currently in a pilot or experimental stage, serves over fifty (50) cities in both East Los Angeles and North Orange Counties in California. Patients in these areas may select the physicians of their choice from a directory of providers rather than going to a designated clinic as is the case with other programs. The patient can be assured by seeing a Medashare physician, should they in fact need special care or consultations in fields outside those of the primary physician, that they can be referred to another Medashare provider who will likewise honor the fiscal policies of the Medashare Program.

This is unlike an individual physician or clinic who is willing to accept Medicare assignment, but has no establishment with physicians, specialists and hospitals to fulfill those patient needs not available at that particular medical office or clinic.

New methods of reducing costs under the Medashare for Medicare Program:

A. *Monitoring.*—Computer terminals can be placed in each Medashare physician's office through which all Medicare charges could be billed to a Medashare main frame computer. Using tape-to-tape communications from that point to the Medicare fiduciary can save money and reduce the processing time of payment to physician providers. This could serve a most important additional purpose of enabling both peer review and cost containment monitoring as they take place within the individual office setting. With a rotating anonymous panel of physicians conducting utilization review, abuse and over-use could be efficiently employed.

B. *Reduced payments to physicians.* This plan has been named by my colleagues "The Zinberg Plan" for reducing the cost of reimbursement to physicians providing services to Medicare recipients. Under this plan the physician who accepts the assignment of benefits could elect an alternative option of receiving 55% of the usual allowable fee instead of 80%. This payment, however, would be made to the provider on a taxexempt basis and the Medicare beneficiary would remain responsible for the normal 20 percent co-payment. Careful analysis will clearly demonstrate by adopting this plan a 25–30 percent savings is made in the outlay of payment to those physicians who elect this optional payment for their services.

In simple terms, those physicians who elect to receive the normal 80¢ or 80% payment on a claim are likely to declare 40¢ of that 80¢ as overhead expenses and 40% would represent taxable income. Even if the provider is in the 50% tax bracket, he or she would then be paying approximately 20¢ as tax revenue. This revenue would be lost under the "Zinberg Plan" option. The savings to Medicare, however, in reduced payment to physicians electing the 55% option is 25¢ to 30¢. This represents a net savings of 5–10¢ on each dollar paid to the Medicare provider.

Approximately 20% of the entire budget is paid to physicians. Of a total budget of 60 billion dollars, physicians' payments account for approximately 12 billion per year. Simple arithmetic then indicates that in its first year or operation, this could save in excess of one billion dollars, even after lost tax revenue is included. This savings could be accomplished almost immediately. With escalating costs anticipated by the growing Medicare population, the savings would probably reach 5 billion dollars by the years 1985 and 1986. Not all physicians would be amenable to accepting this option, but because of the obvious tax advantages, certainly sufficient numbers would.

SUMMARY

Let the American public be totally aware of its options. Let us not urge upon them a grossly Negative National Health Care Policy. While it is essential that we embark upon a program endeavoring to decrease the rate of increase of health care costs, we must likewise improvise a program that improves access, improves utilization and expands services on a continuing basis.

We must not be tempted to take the easy way out through those systems which encourage decreased utilization and services. Instead, let us focus our attention on streamlining cost effectiveness of our health care delivery system by genuine, efficient and productive peer review and most importantly, by dramatically slashing the outrageous administrative costs and regulatory costs. By directing our efforts soley toward reducing those costs related to healthcare providers through increased regulation, we will more than likely increase administrative costs as well as promote the aforementioned negative national health care policy.

Reduction in those expenditures related to administrative and regulatory activities, coupled with serious peer review, will result in a massive infusion of dollars available for an efficient cost-contained program.

Thank you for the courtesies extended to me by this honorable committee.